Developing the Carers' Alert Thermometer for Young Carers (CAT-YC)

Lynn Kettell

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Declaration

This thesis is entirely my own work and has not been submitted, in full, or in part, for the award of a higher degree at any other educational institution. Sections of this thesis have been presented at conferences or disseminated via media outlets, details are presented below:

Conference Presentations

2019 Kettell, L., Knighting, K., Jack, B., O'Brien, M**.** Poster and Oral presentation: 'Findings from Developing the Carers' Alert Thermometer for Young Carers' at Edge Hill University Post-Graduate Research Symposium

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Dedication

This thesis is dedicated to my father Kenneth John Thompson;
a gentle man and gentleman, and the kindest, most
inspirational person I will ever know.

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Preface

Before this thesis begins, I would like to say a little about myself and my reasons for wanting to undertake this doctoral study, as it helps to situate the research and my prior experiences.

My professional background and training is in counselling and psychotherapy, and my last role before embarking on this journey was as a counsellor in a children's hospice. I worked with many young people who had a sibling with a life-limiting condition or terminal illness and was frequently moved to hear of their struggles for support of their own. Often these young people did not talk to family, friends or school staff about their situation and did not know how to broach the subject of asking for support themselves. Some of these young people referred to themselves as 'young carers' and some did not; however it was evident that both experienced similar challenges, regardless of how they self-identified.

For the last 12 years, both before and during my PhD studies, I have also been a foster carer. Many of the children I have looked after were young carers before they came into the social care system. Often this involved caring for a parent, but sometimes it involved caring for younger siblings too. For many of these young people, they were unable to stay with their birth families for safeguarding reasons. However, it was apparent that most of them had provided care over an extensive period of time, without identification, recognition or support. Again, many did not refer to their role as 'caring', it was just what they did in their family.

I am not suggesting these young people should have stayed with their families when there were safeguarding issues that put them at risk of harm, any more than I would not suggest those young carers in the children's hospice should have been removed from their families to relieve them of their role. I simply want to highlight the difficulties and complexities involved when young people have a family member with a long term or progressive illness, disability or health condition. Moreover, a challenge for professionals working with these young people often lies in trying to assess whether the care provided is excessive or inappropriate, or can be supported so that the young person has the best opportunity to flourish.

Being a recent graduate of Edge Hill University, in 2016 I heard about a PhD study to develop a short screening tool for use with young carers. I immediately knew that this was something I had to apply for, as it could potentially result in helping so many young people with caring responsibilities. I met the Director of Studies, Dr Katherine Knighting, and discussed the study at great length. This confirmed to me that I had made the right decision to apply and I was fortunate to be offered the studentship via a graduate teaching assistant position. I have thoroughly enjoyed every moment of this journey and I hope the CAT-YC will be used in the future by many professionals working with young carers in health and social care and education settings.

Abstract

Background: There are approximately 215,000 young carers in the UK, providing unpaid care such as housework, personal care and emotional support to family members. However, the real figure is estimated to be four times higher than this, as many remain hidden from official statistics. The care provided by young people may be long or short term, and when they have unmet needs arising from their caring role, this can impact on their health, well-being, education and transitions into adulthood. It is imperative, therefore, that young carers are triaged for support at an early stage, with ongoing monitoring to ensure they have the best opportunities to flourish.

Aim: The aim of this doctoral study was to identify areas of burden experienced by young carers aged 11-18 and use their views and professionals' views to develop the Carers' Alert Thermometer for Young Carers (CAT-YC). The CAT-YC will act as a short screening tool to triage young carers to appropriate support, or a full assessment of needs, with the additional opportunity for ongoing monitoring of any unmet needs they may have.

Methodology: A pragmatic, mixed-method, multi-phased, consensus approach utilising qualitative and quantitative data collected sequentially from a purposive sample of young carers and professionals via a focus group, interviews, a Delphi survey and consensus group meetings.

Findings: Data from 26 young carers (n=17 individual interviews; n=9 focus group) were thematically analysed and developed into the first round of a 4 round Delphi survey. This was completed either online or at small group meetings by 96 participants in round 2 (n=68 professionals; n=28 young carers) and 110 participants in round 3 (n=74 professionals; n=36 young carers). In round 4, a further 19 members of an expert panel (n=11 young carers; n=8 professionals with a national or regional strategic role in young carer support) reviewed and ranked the final items for the CAT-YC. It was then piloted by three organisations working with young carers and a short evaluation of the pilot study (n=6 professionals; n=4 young carers) tested the readability and usability of the CAT-YC.

Key Words: Young Carer, Delphi, Mixed-Methods, Screening Tool, Assessment of Needs

Chapter One

Introduction and Background

Epigraph:

> *So he kept his mother's trouble secret. There were times when she was calmer and clearer than others, and he took care to learn from her then how to shop and cook and keep the house clean, so that he could do it when she was confused and frightened. And he learned how to conceal himself too, how to remain unnoticed at school, how to not attract attention from the neighbours, even when his mother was in such a state of fear and madness she could barely speak. What Will feared more than anything was that the authorities would find out about her, and take her away, and put him in a home among strangers. Any difficulty was better than that. Because there were times when the darkness cleared from her mind, and she was happy again, and she laughed at her fears and blessed him for looking after her so well; and she was so full of love and sweetness then that he could think of no better companion, and wanted nothing more than to live with her alone for ever.*
>
> From 'The Subtle Knife' (Pullman, 1997: 11)

1.1 Introduction

The epigraph above refers to Will, a character who is a young carer to his mother, in a novel by Phillip Pullman. The underlying message is about love and the strength of family bonds, and although the story is fictitious, for many young people caring for a family member long-term, this may resonate with their reality. Some young people who provide care for a loved one may be afraid to seek support or be unaware of their statutory rights for support. Others do not recognise they are 'young carers' and are often identified by school staff, social services, or health care professionals involved in the care of their ill or disabled family member. Some do recognise their role, and they or their families may contact statutory services or non-governmental agencies and charities working with young carers, who will carry out an assessment to identify if there are any needs arising from a young person's role as a carer that need to be addressed.

This thesis contains an explanation of the process followed to develop a short screening tool for use as part of the assessment procedure used with young carers aged 11-18, of a family member who has a long-term or progressive illness or disability. The aim of this chapter is to set the context for the study by discussing who young carers are and their prevalence in society. As this study focuses on young carers in England, relevant key legislation is discussed along with the principles and purpose of assessment as a means of preventing or reducing any negative consequences from the challenges of caring. It is important to note that although terminology and legislation applies to England, the standards and rationale are often applicable across the whole of the UK due to devolved services. The caring role itself is then considered, and an integrative review of existing literature explores how caring may impact young carers' health, development, education and overall wellbeing. The chapter concludes with a rationale for conducting a further literature review to appraise existing screening and assessment tools for use with young carers.

1.2 Young Carers

There are different conceptual connotations of the term 'young carer' (Cree, 2003; Thomas et al. 2003; Aldridge, 2017), and prior to the introduction of the Care Act (2014) and Children and Families Act (2014), the term 'young carer' did not appear in English legislation. Lack of legal recognition of the term is also an international concern; e.g. in Canada there is no formal policy acknowledging, or recognising, young carers (Stamatopoulos, 2018) and, in Australia, although young people who provide unpaid care have been acknowledged in legislation, no mandatory protective services have been put in place to support any resultant needs they may have (McDougall, O'Connor and Howell, 2018). In the USA young carers, who are often referred to as 'young caregivers', have no specific legal rights, and Leu and Becker (2017:757) argue that "*to date, [in the USA] there has been little attention paid to the particular needs of young carers in policy or service responses."*

Therefore, as the term 'young carer' is often relative and contextual, Doutre, Green and Knight-Elliott (2013) suggest that in England at least, it has most often been defined for administrative purposes. Various researchers, academics and support organisations have offered definitions over time, including the following referred to in the Blackwell Encyclopaedia of Social Work (Davies, 2000:432):

'Young carers are children or young people under the age of 18 who provide care, assistance or support to another family member. Young carers carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent, but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.'

However, although this definition is comprehensive, Aldridge (2017:3) argues the terms 'regular' and 'significant' have created ambiguity and detracted attention away from the impact of caring. Therefore, for the purposes of this study, the legal definition given in the Children and Families Act (2014:72) will be used. This Act defines a young carer as:

'*a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).*'

1.3 Young Adult Carers

There is no corresponding legal definition of a 'young adult carer', as legally once a young carer is 18 they are defined as an adult for legislative purposes in England. However, in order to smooth the transition from children's to adult services, many organisations extend their services to provide support for young carers until they are slightly older, such as the charity Barnardo's, who refer to them as young adult carers, and define them as:

'A young adult carer is someone who is aged 18-25 and provides, or intends to provide, care, assistance or support to an adult on an unpaid basis.'

Some researchers and academics in England refer to young adult carers as being aged up to 25 (Becker and Becker, 2008), although some refer to them more specifically as being 16 – 25, or even 14 - 21 (Aldridge, 2017). In other parts of the world, e.g. the USA, it is common for researchers to include young people who are carers up to the age of 21 (Shifren and Chong, 2012), or even 40 (Leu and Becker, 2017) in their studies. In Australia, researchers often refer to young carers or young adult carers as being under 24 (e.g. Ireland and

Pakenham, 2010; Patterson, Pearce and Slawitschka, 2011). Therefore, although this study focuses on young carers aged 11-18, as the majority of young carers in England (87%) are aged 10-17 (Office for National Statistics (ONS), 2016), it is important to acknowledge the disparity of definitions and age ranges in literature involving young people who are carers.

1.4 Long-term or Progressive Illness or Disability

As reported in the introduction, the short screening tool has been developed for use with young carers aged 11-18 of 'a family member who has a long-term or progressive illness or disability.' The reason for specifying the continuing nature of the illness or disability is to distinguish between those young people who care for a sick relative for a short period of time, as may typically happen in many families, and those whose caring role is experienced over an indeterminable time period (Warren, 2007). Young carers often live in very different family situations to their non-carer peers and even when comparing them with other young carers, it is clear they are not a homogenous group (Doutre, Green and Knight-Elliott, 2013; Aldridge, 2017). Some may have a parent with a progressive or chronic illness, mental health condition or alcohol/substance misuse addiction; some may have a sibling with a severe learning disability, or life-limiting condition (Cree, 2003; Thomas et al. 2003; Dearden and Becker, 2004; Abraham and Aldridge, 2009). Similarly, due to the complexity and composition of family situations, no distinction is made at this stage between whether a young carer is the primary carer in the family or shares their caring role with others. However, this is considered in more detail later in the thesis.

A progressive illness is described as '*a disease or health condition that gets worse over time, resulting in a general decline in health or function*' (Royal College of Nursing (RCN), 2015:3). Progressive illnesses include neurological conditions such as multiple sclerosis, motor neurone disease, Parkinson's disease, but also cancer, rheumatoid arthritis, diabetes, chronic obstructive pulmonary disease, and many others (RCN, 2015). Long-term illness or disability may or may not involve a progressive illness and can include conditions such as asthma, cerebral palsy or autism (Bernell and Howard, 2016). Alternatively, disability can occur as a result of conditions such as stroke/transient ischaemic attacks, or by an accident or injury. Therefore, for the purposes of this study, it is less the classification of illness or disability that

is important to understand, but more the ongoing or cumulative nature of caring that may ultimately impact on the young carer's health and well-being.

1.5 Research about Young Carers

Findings from the first qualitative research study that explored the experiences of young carers in the UK were published in 1993, by the Loughborough Young Carers Research Group (Aldridge and Becker, 1993). Prior to this, there had been several small-scale quantitative studies that provided general statistical and descriptive data on young carers (e.g. Page, 1988; O'Neill, 1988), but none that explored, or documented, the participants' lived experiences. The seminal study, entitled 'Children who care: inside the world of young carers', by Aldridge and Becker (1993) involved 15 young carers and young adult carers aged between 3-35, with a median age of 15. Profiles of each participant were reported, and the nature and extent of caring tasks were explored through individual interviews, providing an insight into a young carer's role for the first time. It is generally acknowledged that this study was the starting point for raising awareness, and initiating further research, about young carers in the UK (Becker and Leu, 2014).

The following decade saw an increase in research studies about and/or with young carers (Warren, 2007). It became evident that unsupported caring, particularly if it happened over a lengthy period of time, could affect a young person's health, wellbeing, education and career opportunities. The increase in awareness of young carers and their needs has also been encouraged by non-governmental organisations in the UK, e.g. the Children's Society and Carers Trust, who have played a key role in campaigning for young carers, ultimately leading to changes in policy and the introduction of new legislation in 2014 (Leu and Becker, 2017).

1.6 Prevalence of Young Carers

The 2011 Census reported there were 178,000 young carers in England and Wales (ONS, 2011). A further 29,000 young carers were reported in Scotland (National Records of Scotland, 2011) and approximately 8,500 in Northern Ireland (Patient and Client Council, 2011), making an official UK total of over 215,000 young carers. In 2010 a study involving 4,029 school children conducted by researchers from Nottingham University, in conjunction with the British Broadcasting Corporation (BBC), estimated the figure to be much higher suggesting

there were approximately 700,000 young carers in the UK (Howard, 2010). This estimated figure has been queried by Aldridge (2017), however, as she highlights flaws in the study design and lack of reliable data to support it. In a recent national survey of young carers in England, carried out on behalf of the Department for Education, 420 households containing at least one young carer were identified out of a sample of 79,629 households (Cheesbrough et al. 2017). This equates to a minimum of 278,000 young carers in the general population in England, although many of these households will contain more than one young carer. Internationally, estimates of young people providing care vary in different countries, but figures suggest it to be between 2% and 8% of all children in advanced industrialised capitalist societies (Leu and Becker, 2017).

Official figures are likely to be underestimated, however, as often individuals providing care remain hidden from formal statistics, perhaps due to them not self-identifying as carers (Carduff et al. 2014; Aldridge, 2017; Phelps, 2017). This could be because of the gradual increase in the caring tasks they perform, or because they see their caring role as integral to the relationship they have with the person they care for (Carduff et al. 2014). Additionally, many more remain hidden due to fear of repercussions for their families in disclosing caring responsibilities, or from a sense of loyalty, fear of stigma or bullying, or simply because they are unaware of support available (Aldridge and Becker, 1997; Department of Health, 2010; The Children's Society, 2013; Phelps, 2017). Many of these hidden issues preventing young carers from seeking support are also reported internationally; e.g. in the USA (Siskowski, 2006), Canada (Stamatopoulos, 2018), Australia (Moore and McArthur, 2007) and New Zealand (Gaffney, 2007).

The next section considers the role of legislation, along with the principles and purpose of assessment as a means of preventing or reducing any negative consequences from the challenges of caring for young people.

1.7 The Role of Legislation Affecting Young Carers

In April 2015, the Care Act (2014) and Children and Families Act (2014) were implemented in England. As stated earlier, prior to this date the term 'young carer' did not appear in English legislation and for a local authority (or social services department) to have an obligation to

support a young person under 18 who provided unpaid care before that date, he or she would have to be considered as a child in need under section 17 of the Children Act (1989). Alternatively, they could be assessed for support under other legislation, but this required proof that they were carrying out substantial caring responsibilities for a significant amount of time (Carers UK, 2016; Aldridge, 2017).

The Children and Families Act (2014) amended the Children Act (1989) by inserting a new section, 17 ZA-ZC, to deliver the changes to the Children Act (1989). Part of these changes meant that a young carer no longer had to qualify their role; they could now be assessed either based on appearance of need or following a request by them or their parent(s). At the same time the Young Carers (Needs Assessment) Regulations 2015, which set out how local authorities must exercise their statutory duties regarding assessments, came into force. These key pieces of legislation replaced six prior pieces of legislation and clarified the law relating to local authorities' legal obligations to identifying, assessing and supporting the needs of all young carers, regardless of the type or amount of care they provide. Relevant parts from each of the Acts are considered further in the following sub-sections.

1.7.1 The Children Act (1989)

The Children Act (1989) was enacted in November 1989 to reform the law relating to the welfare of children and to provide for local authority services for children in need. The first section stipulates that the child's welfare is paramount when making any decisions about their upbringing (the paramountcy principle), that the wishes and feelings of the child must be ascertained, and that every effort should be made to preserve the child's home and family links. Section 17 of the Children Act (1989) defines a child as being in need in law if:

- he or she is unlikely to achieve or maintain or to have the opportunity to achieve or maintain a reasonable standard of health or development without provision of services from the local authority
- his or her health or development is likely to be significantly impaired, or further impaired, without the provision of services from the local authority
- he or she has a disability

Young carers are usually only assessed as a child in need under section 17 of the Children Act (1989) if it is felt there are safeguarding concerns, or that they are unlikely to reach or

maintain a satisfactory level of health and development (Association of Directors of Children's Services (ADCS), 2015). Assessments under this Act must be carried out by a registered social worker (Department for Education, 2015).

1.7.2 Children and Families Act (2014)

Section 96 of the Children and Families Act (2014) states that in the Children Act (1989), immediately after section 17, the following clause (17ZA Young Carers Needs Assessments: England) is added:

1) A local authority in England must assess whether a young carer within their area has needs for support and, if so, what those needs are, if:
    a) It appears to the authority that the young carer may have needs for support, or
    b) The authority receive a request from the young carer or parent of the young carer to assess the young carer's needs for support.

This newer legislation places a duty on local authorities to take 'reasonable steps' to identify young carers who have support needs (Children's Commissioner, 2016:6). Once identified, they must offer an assessment of their needs regardless of the amount or type of care they provide (Carers UK, 2016).

1.7.3 Care Act (2014)

The Care Act (2014) repealed most of the adult social care law in England, including the majority of the previous Carer Acts. The relevant sections relating to young carers are contained in sections 63-64 and refer to a local authority's statutory obligation to assess a young carer, if it appears likely that they will have needs for support after they become 18. The Statutory Regulations and Guidance accompanying the Act highlight that when carrying out an adult's or carer's assessment, if it appears that a child in the family is involved in providing care, the local authority must consider the impact of the person's needs on the young carer's wellbeing, welfare, education and development, and whether any of the caring responsibilities could be inappropriate (Department of Health, 2014). The Guidance is not categorical about what this entails, but suggests examples such as providing personal care e.g. bathing and toileting; carrying out strenuous physical tasks; administering medication; providing emotional support; or maintaining the family budget.

1.7.4 Summary of Legislation

It is clear from the legislation that local authorities in England must offer an assessment where it appears that a young person is providing or intends to provide care. A good young carer's needs assessment should focus on reducing negative outcomes for young carers and provide a plan to help them achieve their aspirations (The Children's Society, 2016). However, there is currently no national standardised assessment for young carers (The Children's Society, 2016). Moreover, section 79 of the Care Act (2014) enables local authorities to delegate almost all of their functions, with the main exception being safeguarding (Carers UK, 2016). This has led to many assessments being outsourced to non-governmental organisations in the third sector (Leu and Becker, 2017). Even with a well-developed legal structure and framework, Leu and Becker (2017) argue that young carers may fall through the gaps in policy and legal safety nets, and between Adult and Children's Services.

The Association of Directors of Adult Social Services (ADASS) (2015) also highlight the confusion sometimes caused by the potential overlapping responsibilities for Adult and Children's Services. The primary responsibility for assessing and responding to the needs of a young carer rests with the service responsible for assessing the person they support, rather than basing it on the age of the carer. Therefore, Children's Services are responsible for assessing the needs of young carers of disabled children (typically siblings), and Adult's Services are responsible for assessing the needs of young carers of adults (typically parents). Furthermore, if Adult's Services suspect a young carer may be a child in need under section 17 of the Children Act (1989), they will need to consult with Children's Services to consider if further action (e.g. a safeguarding investigation) is needed.

Consequently, this means that some young carers' needs may be assessed by professionals who do not have the same familiarity with children's needs as professionals employed by Children's Services (ADASS, 2015). Moreover, although adopting a whole family approach to assessing any needs of both a young carer and the person they care for is an important consideration and should be promoted, ADCS (2015) argue that it is good practice to seek the views of children and adults separately, as it may be very difficult for children to say how they really feel about their caring role in the presence of an adult who may also be the person they

care for. They further suggest that it may be helpful to speak to a young carer's teachers and other relevant adults as part of the assessment process (ADCS, 2015). It is argued by Leu and Becker (2017) that many professionals are unaware of the specific legal requirements placed upon them, and they suggest there is a gap between the ambition and purpose of the law, and the actual implementation on the ground by professionals (such as social workers, healthcare practitioners and teachers) with responsibilities in this area.

In order to understand what needs young carers may have that professionals need to consider as part of their assessment, the following section considers the caring role and what it may involve for young people. Following this a review of relevant literature explores how the caring role may impact young carers' health, development, education and overall wellbeing.

1.8 Understanding the Caring Role

It is important to acknowledge that the role of a young carer can be difficult to conceptualise and may depend on the nature and severity of the illness or disability of the family member needing care (Thomas et al. 2003; Doutre, Green and Knight-Elliott, 2013). It may also be affected by the household composition and role of other family members, whether they live near to other family members who may help, or even be influenced by external factors, such as cultural mores (Nagl-Cupal et al. 2014; Aldridge et al. 2016). It may even be because families cannot afford alternative forms of care (Leu and Becker, 2017). Childhood itself is a socially constructed notion (Thomas et al. 2003; Aldridge, 2017) and families have different levels of expectations when it comes to caring and household responsibilities as a reciprocal part of family life (Cree, 2003; Warren, 2007). As discussed earlier, caring can also develop insidiously over time, with some young people taking on increasing responsibilities, often not realising that they are carers (Smyth, Blaxland and Cass, 2011; The Children's Society, 2013). It can, therefore, be challenging to differentiate between what may be considered a conventional level of caring, and what may be deemed inappropriate or excessive (Warren, 2007; Richardson, Jinks and Roberts, 2009).

As discussed earlier, one of the key principles highlighted in the Care and Statutory Guidance issued under the Care Act (2014), paragraph 2.49, is that '*children should not undertake inappropriate or excessive caring roles that have an impact on their development*', but a

plethora of research findings suggest that many young carers are indeed involved in what may be deemed by some to be inappropriate or excessive levels of caring (e.g. Aldridge and Becker, 1993; Becker, Aldridge and Dearden, 1998; Dearden and Becker, 2004; Abraham and Aldridge, 2009). However, as Cree (2003) and Warren (2007) highlight, different illnesses bring different pressures, and these can fluctuate over time, making it difficult to establish levels of excess or appropriateness. Furthermore, caring frequently involves emotional as well as physical work and it can be difficult to separate some aspects of the caring role from the wider impact of illness or disability on family life (Thomas et al. 2003; Doutre, Green and Knight-Elliott, 2013).

Therefore, in order to try and establish how caring may impact young carers, it is important to understand what caring may involve, so that any excessive burden may be recognised. Whilst not exhaustive, Figure 1 below contains a list of typical caring tasks that a young person may provide or be involved with. All of the activities listed have been reported extensively in existing literature and can involve one or any combination of the tasks below (Aldridge and Becker, 1993; Thomas et al. 2003; Dearden and Becker, 2004; Warren, 2007; Aldridge et al. 2016; Cheesbrough et al. 2017).

- Provide practical support, e.g. assistance with domestic tasks such as cleaning, laundry, shopping, cooking
- Provide physical support, e.g. lifting or assisting with mobility
- Provide personal care, e.g. washing, toileting, dressing
- Provide emotional support, e.g. listening, keeping company
- Caring for siblings, e.g. taking to school, feeding, putting to bed
- Attending appointments and/or helping with medication
- Interpreting and/or translating, e.g. where there are communication difficulties
- Helping with financial matters, e.g. paying bills or maintaining the family budget

Figure 1: List of typical caring activities

1.9 Literature Review of Impact from Caring

As a consequence, the impact from caring can vary widely, and to understand how young carers' health and wellbeing may be affected by this, a review of literature surrounding impact was conducted to address the following question:

'*What is the impact of caring, if any, on young carers' health and well-being?*'

An integrative review was chosen as it can contain literature from qualitative and quantitative research studies and theoretical sources, and adopts a critical and systematic approach (Whittemore and Knafl, 2005).

1.9.1 Search Strategy for Reviewing Impact from Caring

An initial search strategy for considering this question was created in October 2016 and was updated in March 2019. Titles and abstracts of studies from the electronic databases: CINAHL (Cumulative Index of Nursing and Allied Health Literature), Wiley, Academic Search Premier (EBSCO) and PsycINFO were searched as these were deemed most relevant to the topics of health and social care. The inclusion criteria were restricted to searches of studies involving young carers aged 18 and under that were undertaken during the last 26 years (1993 – present), as this is the approximate period of time from when research involving young carers began (Aldridge and Becker, 1993; Leu and Becker, 2014). Further restrictions were to include literature published in the English language only, as the costs of translation were not feasible for this study. Table 1 below displays the inclusion and exclusion criteria for papers to be reviewed.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria:	**Exclusion Criteria:**
Conducted between 1993 – present	Studies not meeting the inclusion criteria
Written in English language	
Related to young carers aged 18 and under (at time of caring role)	

Key words and terms were used separately and then in combination, with Boolean operators applied, where necessary, for a more focused search. Key terms included: "young carer*" OR "young caregiver*"; "burden OR stress OR strain"; and "impact". Table 2 depicts the results of the search.

Table 2: Number of Hits Across Databases (March 2019)

	Search Terms	Wiley	CINAHL	Academic Search Premier	PsycInfo
1	"young carer*" OR "young caregiver*"	138	88	211	138
2	"burden OR stress OR strain"	209,936	137,472	927,954	165,983
3	"Impact"	204,934	165,717	975,401	218,629
4	1 & 2	37	14	17	16
5	1 & 3	22	19	34	16
6	4 & 5	8	19	5	5

It has been argued by Conn et al. (2003) that methodological rigour does not differ between published and grey literature. Therefore, in order to encompass all of the factors related to the review question, searches for grey literature were conducted via Google Scholar and Edge Hill University's (EHU) Discover More search engine. Additionally, hand searching reference lists of identified published articles was used for comprehensiveness. Duplicates were removed, together with literature not meeting the inclusion criteria for this review, such as those not published in English or related to young carers aged 18 and under. Finally, publications from countries that are culturally very different to the UK, e.g. India, Sub-Saharan Africa and Korea, were excluded as they are unlikely to be comparable. The remaining literature was then read in full and further exclusions were made, such as articles not relevant to addressing the review question in section 1.9 earlier. Although this was not a systematic review according to the usual accepted definition (Moher et al. 2009), it did draw on the typical process followed. Please see Figure 2 on the following page for a PRISMA type flow chart depicting this process (PRISMA relates to the Preferred Reporting Items for Systematic reviews and Meta-Analyses, Moher et al. 2009).

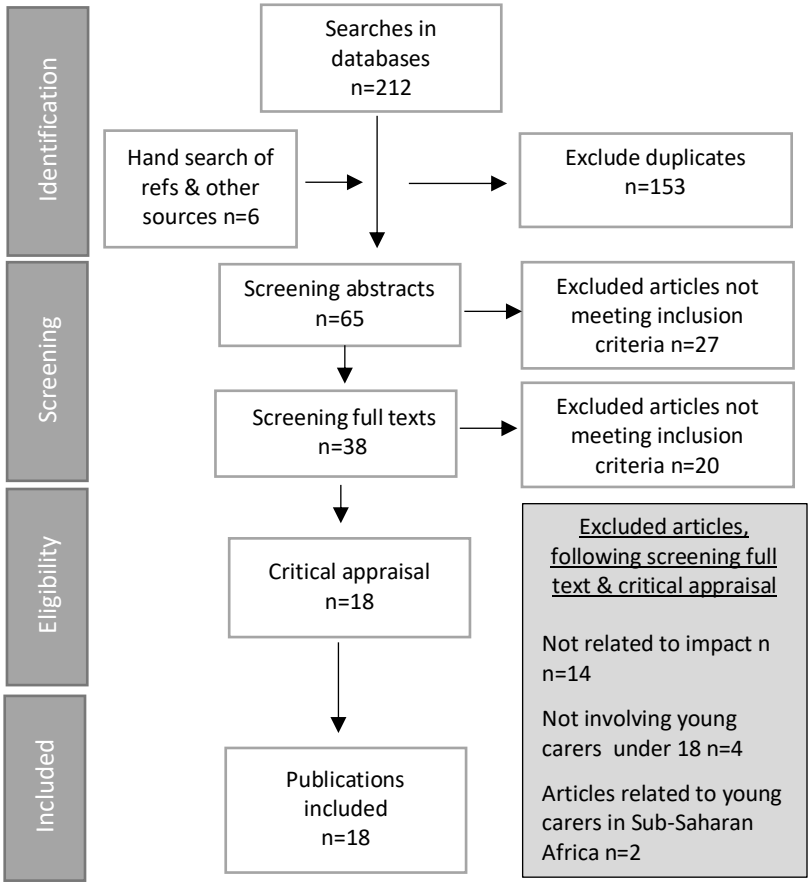


Figure 2: Adapted PRISMA flow diagram of study selection process for literature review of impact from caring

1.9.2 Overview of Eligible Literature

Eligible literature consisted of 14 empirical studies, two systematic reviews and two reports containing UK government commissioned data about young carers. Information is provided in the next section about the process of critically appraising them for consideration of inclusion in the review.

1.9.3 Methods of Quality Appraisal

The two published reports were detailed and comprehensive, drawing on UK government commissioned data about young carers that provided an essential and significant insight into the research area (The Children's Society, 2013; Department for Education, 2016). These were appraised for credibility and quality, as recommended by Cronin, Ryan and Coughlan (2008). The two systematic reviews were also comprehensive and deemed good quality: a meta-synthesis of qualitative studies (Rose and Cohen, 2010); and a systematic review of young carers and their needs from 2007-2017. This latter study contains useful information of

research conducted in German language speaking countries, but reported in English, further demonstrating the international nature of young carers' needs (Chikhradze, Knecht and Metzing, 2017). The systematic reviews were evaluated using the Critical Appraisal Skills Programme (CASP) Systematic Review Guide (2017) and a scoring system of: 2 = fully addressed; 1 = partially addressed; 0 = not addressed; NC = Not Clear; and N/A = Not Applicable was used, see Table 3 at the end of this chapter. It should be noted, however, that these scores are subjective, as the CASP guides were designed to be used as educational pedagogic tools, as part of a workshop setting, and do not advocate a particular scoring system.

Altogether, from the 14 empirical studies, nine were methodically evaluated using the checklist from the Critical Appraisal Skills Programme (CASP) Qualitative Checklist Guide (2017) and five were evaluated using the Joanna Briggs Institute (JBI) Checklist for Analytical Cross-Sectional Studies (Moola et al. 2017). The same scoring system as before was used to help appraise the quality of the articles, i.e. 2 = fully addressed; 1 = partially addressed; 0 = not addressed; NC = Not Clear; and N/A = Not Applicable. Results from the appraisals are displayed in Tables 4 and 5 at the end of this chapter.

1.9.4 Inclusion for Review

None of the literature reviewed was excluded following appraisal, as all appeared to be valuable to aid understanding of how young carers can be impacted by their role. Although Whittemore and Knafl (2005) infer there is no gold standard for quality appraisal in integrative reviews, the standard of reporting was nonetheless generally high, although the recruitment strategies used, and authors' reflexivity were areas with less reported detail in at least half of the qualitative studies. An overview of the included studies is presented in Table 6 on the following pages. Data addressing the review question were extracted and thematically analysed (Braun and Clarke, 2006), and several themes were identified: the impact of caring on young carers' health and wellbeing; the psychosocial impact of caring on young carers' identity and self-esteem; social life and life satisfaction; and education and career aspirations. Each theme is discussed in more detail and helped inform the development of interview and focus group questions later in the study.

Table 6: Literature for consideration in review

Author(s) (year)	Study type method (location)	Aim(s)	Sample	Quality Appraisal Score	Summary of main findings (key points)
Becker & Sempik (2018)	Cross-sectional Online survey (UK)	To explore the relationship between extent of caring & perceived mental health problems and impact of caring responsibilities on education & work	295 young carers aged 14-25	15/16	• 45% of respondents reported having a mental health condition • 31% reported being bullied due to their caring role • 45% felt they underachieved at school due to their caring role
Bjorgsvindottir & Halldorsdottir (2013)	Phenomenology Interviews (IPA) (Iceland)	To explore experiences of young carers caring for a lone parent with multiple sclerosis	11 young carers aged 5-18 at time of caring	17/20	• Participants felt silent, invisible & unacknowledged as carers • More communication, information & support from professionals needed
Bolas, Van Wersch & Flynn (2007)	Phenomenology Interviews (IPA) (UK)	To explore the personal experiences of young carers in relation to their well-being	5 young carers aged 14-18	16/20	• Participants felt overwhelmed & frustrated by relentlessness of caring role • Caring was isolating & could be stigmatising • Possible positive emotional benefits from feeling useful
Cassidy, Giles & McLaughlin (2014)	Cross-sectional Survey (UK)	To explore if there were any positive effects from caring role to young carers' own health & well-being	442 young carers aged 12-16	12/16	• Benefit finding related to social recognition of caring role, support and feeling valued • Benefits decrease with higher levels of caregiving
Chikhradze, Knecht & Metzing (2017)	Systematic review N/A	To summarise knowledge about young carers, with focus on experiences, impact, needs & coping behaviours	25 studies reviewed of young carers aged 4-25	15/18	• Young carers conceal their caring role from others • Reduced social experiences • More help requested to alleviate negative impacts from role

Author(s) (year)	Study type method (location)	Aim(s)	Sample	Quality Appraisal Score	Summary of main findings (key points)
Clabburn & O'Brien (2015)	Qualitative Interviews (IPA) (UK)	To explore how providing care for a parent with motor neurone disease (MND) impacts on a young person's life	7 former young carers aged 8-18 when MND diagnosed	15/20	• Guilt from challenges to balancing social life with caring role • Confusion & loneliness from lack of information about illness • Education positively affected & provided escapism from role
Collins & Bayless (2013)	Cross-sectional Survey (UK)	To investigate the impact of caring for a parent on the psychosocial development of a young person	20 young carers & 20 non-caring peers aged 11-18	16/16	• Lower life satisfaction & self-esteem reported in young carers • More difficulties with peer relationships through limited social opportunities
Cree (2003)	Qualitative Survey & Interviews (UK)	To explore the worries and problems of young carers	61 young carers aged 10-15	17/20	• Young carers reported significant worries about their own & family member's well-being & future • Problems increased with length of time in caring role
Department for Education (2016)	Qualitative Interviews (UK)	To find out more characteristics of young carers, the nature of their caring role, impact of caring & experiences of support	22 young carers aged 6-17	N/A	• Participants reported anxiety, stress & tiredness • Under-engagement in education • School holidays more challenging, due to increased responsibilities
Earley, Cushway & Cassidy (2007)	Qualitative Focus groups (UK)	To explore the experiences of young carers to try to understand what they are thinking & feeling in an effort to cope with caring role	17 young carers aged 10-16	16/20	• Participants had conflicting feelings about caring role • Burden of responsibility & difficulty 'switching off' frequently reported
Moore, McArthur & Morrow (2009)	Qualitative Interviews (Australia)	To understand young carers views about school, engaging with education & peers, and support	51 young carers aged 12-21	16/20	• Participants capacity to engage with education was significantly affected by higher levels of caring • Better support needed & more understanding by professionals

Author(s) (year)	Study type method (location)	Aim(s)	Sample	Quality Appraisal Score	Summary of main findings (key points)
Nagl-Cupal et al. (2014)	Cross-sectional Survey (Austria)	To explore the prevalence and effects of caregiving on young people	335 young carers from sample of 7,403 children aged 10-14	11/16	• Prevalence rate suggests 3.5% of population aged 5-18 in Austria are young carers • Higher levels of physical adverse effects reported in young carers
Nicholls et al. (2016)	Qualitative Interviews (IPA) (UK)	To explore the unmet needs in young adults caring for a parent with a chronic health condition	7 young carers aged 16-24	17/20	• Participants wanted more information & acknowledgment • Better support & respite needed • Caring role is emotionally & psychologically demanding
Richardson, Jinks & Roberts (2009)	Qualitative Focus groups (UK)	To evaluate three young carer projects, focusing on experiences of young carers, peer support & purposeful activities	24 young carers aged 11-16	18/20	• Participants felt different to non-caring peers & some were bullied • Peer support was valuable for reducing loneliness • Projects provided respite & opportunity for new activities
Rose & Cohen (2010)	Systematic review (meta-synthesis of qualitative studies) N/A	To explore young carers accounts of caring & promote phenomenological understanding of experiences	11 studies reviewed involving young carers aged under 25	14/16	• Relationship between caregiving & identity formation suggested • Social lives & friendships restricted by caring tasks • High prevalence of negative social judgement & attitudes reported
The Children's Society (2013)	Report based on data from Longitudinal Survey of Young People in England (LSYPE) (UK)	To discuss findings from LSYPE & gain insight into daily lives & outcomes for young carers	689 young carers aged 13-14	N/A	• Young carers gain fewer qualifications & with lower grades than non-caring peers • Less social opportunities & time with friends reported • School attendance affected by caring responsibilities
Thomas et al. (2003)	Qualitative Interviews & a focus group (UK)	To explore the characteristics & experiences of young carers and their hopes for the future	27 young carers aged 9-18	18/20	• Sadness, worry, anxiety & difficulties with friends reported • Difficult to distinguish differences between impact from caring & impact from having an ill family member

Author(s) (year)	Study type method (location)	Aim(s)	Sample	Quality Appraisal Score	Summary of main findings (key points)
Warren (2007)	Cross-sectional Survey (UK)	To explore if there are differences in impact between being a young carer and having an ill family member but no caring responsibilities	378 non-young carers & 12 young carers aged 9-18	15/16	• Young carers less likely to consider further or higher education than non-carers • Young carers have less opportunities to engage in social activities than non-carer peers

1.9.5 The Impact of Caring on Health and Wellbeing

Eleven of the studies reviewed reported how young carers' own health can be compromised or at risk as a consequence of their caring role. A quantitative research study that aimed to explore the prevalence and effects of caregiving on young people found there were 335 young people who were carers out of a sample of 7,403 children aged 10-14 in Austria (Nagl-Cupal et al. 2014). The study used self-reported questionnaires to collect data and found that participants who identified as being young carers disclosed a significantly higher level of physical ill health, such as headaches or backache than their non-carer peers (e.g. 31.8% vs. 18.6%) (Nagl-Cupal et al. 2014). Similarly, frequent headaches, pains and somatisation were reported to affect young carers by Collins and Bayless (2013) in their comparative study involving 20 young carers and 20 non-caring peers aged 11-18 in England. However, Chikhradze, Knecht and Metzing (2017) noted that physical health issues were rarely reported in their systematic review of 25 studies, which mostly involved short cross-sectional surveys about young carers growing up with chronic illness in the family. They suggested this lack of reported data could be due to the nature of the design of the studies and argued that longitudinal studies would be more likely to establish any physical effects such as exhaustion, or long-term consequences like chronic backache.

Several studies reported difficulties young carers experienced with their mental health (Earley, Cushway and Cassidy, 2007; Nagl-Cupal et al. 2014; Nicholls et al. 2016; Becker and Sempick, 2018). Almost half (45%) of the 295 young carers aged 14-25 in the study by Becker and Sempick (2018) reported having a mental health problem themselves. That study aimed to explore the relationship between the extent of caring and any perceived mental health problems that were reported by respondents in an online survey. Depression, anxiety and stress were reported by Nicholls et al. (2016), which significantly correlated to unmet needs young carers experienced resulting from their caring role. Furthermore, some participants in this study explained that the emotional toll of caring was ever-present, as they were often not just caring for their ill relative, but also caring for, or protecting, the wider family. However, this study only considered the views of seven young carers, all of whom were aged 17-19, and is therefore unlikely to be representative of all young carers. Anxiety about their

family member's welfare when they were away from them was also reported by Earley, Cushway and Cassidy (2007). Furthermore, they reported some young carers experienced anticipatory anxiety and found it difficult to switch off from their responsibilities when away from home. Their qualitative study used focus groups to collect data and involved 17 young carers aged between 10-16. Stress levels were particularly affected by the pervasive nature of caring, with one participant describing it as '*making me sick and all that'* (Earley, Cushway and Cassidy 2007:77).

This theme was also noted by Bolas, Van Wersch and Flynn (2007), who reported that some participants in their small qualitative study involving five young carers aged 14-18, described the relentlessness of caring as overwhelming at times and this sometimes left them feeling angry. They suggest the participants' anger was amplified by frustration over their perceived lack of choice about their caring role. Although lack of choice or autonomy was noted in the study by Bjorgvinsdottir and Halldorsdottir (2013), it was reported by Chikhradze, Knecht and Metzing (2017) that many young carers in the studies they reviewed valued their role and the opportunity to help their families. Some positive benefits for young carers' emotional health were also found by Bolas, Van Wersch and Flynn (2007), including increased self-esteem, linked to feeling useful and capable, together with feeling a sense of pride in their role. Similarly, Cassidy, Giles and McLaughlin (2014) noted that young carers who found benefit in their role and felt recognised and valued, reported higher levels of resilience and better mental health. However, using skills gained to highlight positive attributes such as feeling useful is equivocal and may serve to exacerbate the negative nature of caring.

Worry was cited as an issue for young carers by Nagl-Cupal et al. (2014), although the authors did not elaborate on how, or even if, this was connected to their caring role. Indeed, many adolescents without caring responsibilities may cite worry as an issue, for a variety of different reasons. The primary reason for worry, reported by 82% of participants in a qualitative study involving 51 young carers aged 12-21 in Australia, was concern about their family member's health (Moore, McArthur and Morrow, 2009). This supports the findings by Thomas et al. (2003), who suggested that worrying about their family member's health may have been related to a fear of being taken into care. Conversely, in the study by Nicholls et al. (2016), some participants stated their biggest worry was about inheriting the same health

condition as their parent. However, as a potentially positive consequence, this had made them more aware of their own health needs. Similarly, in a survey of 61 young carers, most of whom were aged 10 - 15, Cree (2003) reported that 67% of the respondents worried about their own as well their family member's health, and many of the respondents had difficulty sleeping and eating. These findings correspond with the views of Chikhradze, Knecht and Metzing (2017), who also concluded, in their systematic review, that worry was omnipresent in young carers' lives.

1.9.6 The Psychosocial Impact on Identity and Self-Esteem

Twelve of the studies reviewed had findings suggesting the impact from caring could affect a young carer's developing sense of identity and self-esteem. Although increased self-esteem was reported by Bolas, Van Wersch and Flynn (2007), both Moore, McArthur and Morrow (2009) and Collins and Bayless (2013) found the lack of opportunity for social interaction with their peers, and a sense of false maturity, had a negative impact overall on self-esteem and identity development during adolescence. Similarly, Rose and Cohen (2010) found, in their meta-synthesis of 11 qualitative studies, that young carers' exploration of alternative identities may have been limited by practical or financial impacts of caring, or their sense of obligation and loyalty to their family, which was often underpinned by feelings of guilt. They suggest this could result in a self-image constructed around the caring role and lead to 'parentification', whereby young carers adopt responsibilities traditionally associated with parents (Earley, Cushway and Cassidy (2007:75). The concept of parentification, however, has been criticised by Cassidy, Giles and McLaughlin (2014), who argue that parentification literature is based on clinical observations of obsessive caregiving in adults. Similarly, no evidence of this was found by Bjorgvinsdottir and Halldorsdottir (2013), who argued that none of the young carers in their study felt they parented their parents. However, this qualitative study of Icelandic young carers of a lone parent with multiple sclerosis may have cultural sensitivities, as the authors noted there was no statistical data about young carers in Iceland, and scarce recognition of them as a group.

Lack of information about their family member's illness or condition has been highlighted as upsetting for young carers in several studies (Earley, Cushway and Cassidy, 2007; Bjorgvinsdottir and Halldorsdottir, 2013; Nicholls et al. 2016). Confusion about their parent's

condition and prognosis led to catastrophising thoughts by some young carers (Earley, Cushway and Cassidy, 2007). Similarly, Bjorgvinsdottir and Halldorsdottir (2013) reported young carers received very little information about their parent's condition from healthcare professionals and believed their parents also had limited information, in turn contributing to a sense of uncertainty and tension in the household. However, as Nicholls et al. (2016) noted, distressing information is usually suppressed by a parent's well-intentioned desire to protect their child. Their study on the unmet needs of young adults with a parent with a chronic condition, however, suggested that some young carers wanted to be informed at each stage of their parent's illness, as it promoted trust and helped them prepare for the future, thereby facilitating emotional coping (Nicholls et al. 2016).

As well as a lack of information, there was a lack of acknowledgement about their caring role from others reported by young carers (Moore, McArthur and Morrow, 2009; Bjorgsvindottir and Halldorsdottir, 2013; Cassidy, Giles and McLaughlin, 2013). Findings from the study by Nicholls et al. (2016) indicate that acknowledgement from non-carer peers was more likely to be forthcoming if the young carer's family member had a potentially terminal illness, such as cancer. These findings suggest that non-carer peers are unlikely to understand the impact from caring on their friend if they do not view the health condition as 'serious' (Nicholls et al. 2016:4). For some young carers, feeling unacknowledged impacted on them negatively, adding to the aura of silence accompanying their parent's condition (Rose and Cohen, 2010; Bjorgsvindottir and Halldorsdottir, 2013). This may also have affected their sense of identity, with some young carers feeling that their role was almost shameful and best kept hidden from their friends at school, to help prevent bullying and stigmatisation (Warren, 2007; Richardson, Jinks and Roberts, 2009; Rose and Cohen, 2010; The Children's Society, 2013). Similarly, Moore, McArthur and Morrow (2009) found that some young carers chose not to disclose their caring role to peers at school because they did not want to be treated differently as a consequence. As Rose and Cohen (2010) indicated, there appears to be an inherent frustration for some young carers in their dilemma of preserving their carer identity, whilst simultaneously wanting acceptance from others.

An interesting suggestion regarding gender identity was proposed by Bolas, Van Wersch and Flynn (2007) in their research of the well-being of young carers in North East England. They

suggested a male participant's reluctance to disclose his caring role to friends at school appeared to have been motivated by fear of threat to his emerging masculinity. Conversely, Earley, Cushway and Cassidy (2007) reported that a young male carer in their study felt his female peers saw him as being more caring because of his role. However, these suggestions may be culturally situated and therefore may not be representative of other young male carers. Indeed, all of the studies reviewed, except two (Earley, Cushway and Cassidy, 2007; Richardson, Jinks and Roberts, 2009), reported much higher levels of female young carer participants than males. This is an area that Chikhradze, Knecht and Metzing (2017:13) argue needs further research, in order to prevent girls taking up 'early caregiving careers.' In the next subsection, the psychosocial impact of caring on social life and life satisfaction is considered, starting with a continuation of the theme of acknowledgement and recognition.

1.9.7 The Psychosocial Impact on Social Life and Life Satisfaction

Eleven of the studies reviewed had findings suggesting young carers' social life and life satisfaction were affected by their caring role. A quantitative survey-based study in the UK was conducted by Cassidy, Giles and McLaughlin (2014) to try to identify benefit finding and resilience in young carers aged 12-16. Accurate records were not kept regarding the total number of families contacted over the two-year recruitment period, but it was estimated that the 442 young carers who responded represented approximately 50% of the potential sample targeted. Findings indicated that when young carers felt their role was socially recognised, they were more likely to feel valued, and support groups provided opportunities for this to happen. Similarly, in a qualitative study involving 24 young carers aged 11-16, Richardson, Jinks and Roberts (2009) reported their participants felt peer group support helped them feel less alone and gave them the opportunity to not just have time away from caring, but also to make friends and try new activities.

However, not all carers have the opportunity to attend support groups, either through lack of awareness, or lack of their own self-identity as carers, as highlighted by Carduff et al. (2014), or perhaps for practical reasons, such as lack of time (Earley, Cushway and Cassidy, 2007) or difficulties with transport (Warren, 2007; Moore, McArthur and Morrow, 2009). Some may autonomously choose not to attend, and this could partly be as a consequence of having so few opportunities to exercise choice in their everyday lives (Bolas, Van Wersch and Flynn,

2007; Bjorgsvindottir and Halldorsdottir, 2013). A salient point was noted by Thomas et al. (2003), that many local authorities have faced budget cuts and austerity measures resulting in a reduction of projects supporting young carers, both specifically through dedicated groups, and in the wider community.

Some young carers avoided social situations and withdrew from the company of others, as they felt talking about their situation might make it worse (Bolas, Van Wersch and Flynn, 2007; Moore, McArthur and Morrow, 2009). For one of the participants in the study by Bolas, Van Wersch and Flynn (2007), there was a fear that talking to others about her mother's ill health only served to reinforce fears that her mother was dying; therefore, social encounters were avoided as much as possible. The study by Moore, McArthur and Morrow (2009) highlighted how some young carers were reluctant to invite friends back to their home, as they were embarrassed about their family member's health condition, or associated behaviour in some instances. Similarly, Thomas et al. (2003) suggest that participants in their study of 21 young carers aged 9-18, faced the most difficulty with friends if they were supporting a parent with a mental health condition, or drug or alcohol related problem. These findings are also consistent with those noted by Chikhradze, Knecht and Metzing (2017), who suggest some young carers feel ashamed of their relative's physically impaired appearance or by assistive devices they have in the household.

Additionally, some young carers reported feeling their caring role set them apart from peers, thereby inhibiting them from forming new relationships (Richardson, Jinks and Roberts, 2009; Rose and Cohen, 2010). This potentially compounded the sense of isolation they felt and created additional barriers to seeking support. Some parents of young carers regarded their children as often having difficulties with their peer friendships, thereby reflecting social rejection or exclusion, and thus intensifying isolation (Collins and Bayless, 2013). This in turn was felt by the researchers to contribute to overall lower levels of life satisfaction for young carers than their non-caring peers (Collins and Bayless, 2013). Although Bjorgsvindottir and Halldorsdottir (2013) do not report the exact figures, they note that most of the 11 participants in their study reported feeling periodically isolated from their friends when their caring role intensified or became particularly demanding. This could of course be for

pragmatic reasons due to lack of time, and therefore assumptions cannot be made that they were intentionally rejected or excluded.

Similarly, lack of time and being too busy with care related responsibilities were reported by participants in the study by Earley, Cushway and Cassidy (2007). However, Bolas, Van Wersch and Flynn (2007) argue that young carers are sometimes less likely to seek support from others when feeling stressed, because disclosing distress involves revealing negative thoughts or feelings, which may result in adverse judgement or rejection. This supports the suggestion by Moore, McArthur and Morrow (2009) that some young carers find it difficult to engage with others when times are difficult, as they perceive a lack of understanding from their friends. In the final subsection, the potential psychosocial impact of caring on young carers' education is considered.

1.9.8 The Psychosocial Impact on Education and Career Aspirations

Eleven of the studies reviewed had findings suggesting the caring role could impact on young carers' education and future career aspirations. A cross-sectional survey of 390 young people in England aged 9-18, of whom 12 were known to be young carers, reported that young carers were more likely to be late for, or miss school than their non-caring peers (Warren, 2007). Similarly, an Australian study of young carers by Moore, McArthur and Morrow (2009), found that more than half of the 51 participants felt their caring role negatively impacted on their attendance at school. Moreover, data retrieved from the Longitudinal Study of Young People in England (LSYPE), commissioned by the Department for Children, Schools and Families, found young carers achieved on average nine general certificate of secondary education (GCSE) grades lower overall than their peers (The Children's Society 2013). This six-year study exploring young people's journey through compulsory education started in 2004 with 15,427 pupils aged 13-14, 689 of whom identified themselves as being carers. It ended in 2010 with over 9,000 young people in the original cohort still completing questionnaires, therefore providing a rich source of data. Additional findings from the LSYPE showed that 5% of young carers missed school due to their caring responsibilities at home, with one in three of those missing school doing so at least once or twice each month (The Children's Society, 2013).

A report published by the Department for Education (DfE) (2016) concluded that some young carers struggled to maintain a good level of engagement at school, as they were tired or preoccupied with worrying about their parent, making it difficult to concentrate in class. This sometimes resulted in young carers missing deadlines or staying at home, thereby making academic achievement more difficult to attain (DfE, 2016). The long-term implications for this are reduced opportunities in further education and/or employment. This confirms the findings from the LSYPE that young carers aged 16-19 are more likely to not be in education, employment or training (NEET) (The Children's Society, 2013). Similarly, Warren (2007) found that young carers were more likely to identify barriers that might prevent them from achieving their future ambitions than their non-caring peers. She suggests these were due to a lack of financial resources, the need to look after their ill or disabled family member, and a lack of qualifications (Warren, 2007).

For some young carers, particularly those in lone parent households, the motivation to achieve in school may have been related to the desire to secure a good job or career after leaving education, in order to contribute financially to the family (DfE, 2016). Motivation in school was also noted by Clabburn and O'Brien (2015), who identified a drive to achieve educational success among some of their participants, often fuelled by the desire to make their families proud. Their study analysed qualitative data collected from semi-structured interviews with a purposive sample of seven former young carers who were bereaved or providing care for a parent with motor neurone disease.

Problems balancing school, homework and caring responsibilities were more evident where school staff were unaware of a young carer's situation at home (DfE, 2016). In some instances, this could be due to the reasons highlighted earlier regarding self-identification (Carduff et al. 2014). However, some young carers chose to keep their caring role hidden as they were reluctant to be singled out or seen as different by either their peers or school staff (Bolas, Van Wersh and Flynn, 2007; DfE, 2016). In some studies, young carers felt they had been treated differently or bullied by peers as a consequence of their young carer status (Cree, 2003; Richardson, Jinks and Roberts, 2009; Moore, McArthur and Morrow, 2009). Moreover, research findings by Clabburn and O'Brien (2015) and Moore, McArthur and Morrow (2009) indicated some young carers also valued school for the respite it provided from their caring

role. A particular strength of the study by Moore, McArthur and Morrow (2009) was that the researchers employed a young carer as a project consultant when analysing the qualitative data collected and also focused on what support young carers would like from their schools.

For those schools that were aware of young carers' family situations, there appeared to be inconsistencies in their approaches (Thomas et al. 2003; Bjorgsvindottir and Halldorsdottir, 2013; DfE, 2016). Some young carers felt well supported by their schools (DfE, 2016), however, others felt their schools displayed a lack of understanding about the difficulties they faced (Moore, McArthur and Morrow, 2009; Clabburn and O'Brien, 2015). Findings from Rose and Cohen's (2010) systematic review, suggest that school staff were more likely to be understanding if a young carer's family member had a physical illness such as cancer, rather than a mental health condition, drug or alcohol dependency, or learning difficulty. Moreover, some young carers suggested teachers could have been more supportive, but their schools lacked structured policies or procedures to address their needs (Moore, McArthur and Morrow, 2009; Bjorgsvindotttir and Halldorsdottir, 2013). Conversely, Thomas et al. (2003) noted that some young carers felt staff at their schools were over-intrusive, resulting in frequent and sometimes unwanted questions about the family member they cared for.

1.9.9 Summary of Impact from Caring

It is important to acknowledge that a caring role can have positive impacts for some young people, such as helping them feel valued, or a sense of pride in what they are doing to help their family. However, these positives must be balanced with evidence that some young carers feel obligated to provide care. Worry, stress and anxiety were often reported in the studies reviewed illustrating how the caring role can negatively affect a young carer's emotional wellbeing. Many young carers stated they felt unacknowledged by peers and professionals, and this sense of feeling different or ignored could be isolating. There was evidence to suggest that those who felt recognised and understood were more likely to feel valued and supported, resulting in better mental health. The review also highlights a paradox for young carers between wanting to do well at school, and the difficulties they faced balancing school work with their caring responsibilities.

It is clear, therefore, that undertaking a caring role can have a negative impact on a young carer's health, development, education and overall wellbeing. Moreover, it is when caring produces a negative impact that young carers are at risk of not achieving their potential, and that is where legislation should be used to help identify, assess and support any needs arising from the caring role.

1.10 Chapter Summary

This chapter has provided background information about who young carers are and how they can be defined both in law and by academics and organisations working with them. The role of legislation was discussed and established the legal requirements in carrying out an assessment of any needs a young carer may have as a result of their caring role. However, the discussion also highlighted the confusion often surrounding the assessment process and the importance of ensuring pertinent information is systematically gathered and recorded after discussion with the young carer. Clearly, the role of a young carer is difficult to define, due to the disparate situations in which they live. Moreover, although young carers are often highly motivated to help their families, they may not recognise the emotional as well as physical toll the role can take on their health and wellbeing. A review of literature was undertaken to understand how their lives may be impacted by the role they perform. Young carers are entitled to the same access to health care, education and enriching social opportunities as other children who do not undertake a caring role, and professionals need to be proactive in asking what needs to be done if their caring role compromises their potential. The assessment process, and the tools used to support it, will be discussed in more detail in the next chapter.

Appendix to Chapter One

Table 3: Scores for CASP (2017) Checklist for Systematic Reviews

Questions for Systematic Reviews	Chikhradze, Knecht and Metzing (2017)	Rose and Cohen (2010)
1) Did the review address a clearly focused question?	2	2
2) Did the authors look for the right type of papers?	2	2
3) Were all of the important, relevant studies included?	NC	NC
4) Did the reviews' authors do enough to assess the quality of the included studies?	2	2
5) If the results of the review have been combined, was it reasonable to do so?	2	N/A
6) What are the overall results of the review?	2	2
7) How precise are the results?	2	2
8) Can the results be applied to the local population?	1	2
9) Were all the important outcomes considered?	2	2
10) Are the benefits worth the harms and costs?	N/A	N/A

Table 4: Scores for CASP (2017) Checklist Guide for Qualitative Studies

Studies	Aims	Methodology	Design	Recruitment Strategy	Data Collection	Reflexivity	Ethics	Data Analysis	Findings	Value	Total
1) Bjorgsvindottir and Halldorsdottir (2013)	2	2	2	1	2	1	2	2	2	1	17
2) Bolas, Van Wersch and Flynn (2007)	2	2	1	1	2	2	1	2	2	1	16
3) Clabburn and O'Brien (2015)	2	2	1	1	2	0	2	2	2	1	15
4) Cree (2003)	2	2	2	2	2	0	1	2	2	2	17
5) Earley, Cushway and Cassidy (2007)	2	2	2	2	2	0	0	2	2	2	16
6) Moore, McArthur and Morrow (2009)	2	2	2	2	2	0	2	1	1	2	16
7) Nicholls et al. (2016)	2	2	2	2	2	0	2	2	2	1	17
8) Richardson, Jinks and Roberts (2009)	2	2	2	2	2	0	2	2	2	2	18
9) Thomas et al. (2003)	2	2	2	1	2	0	2	2	2	2	18

Table 5: Scores for JBI (2017) Checklist Guide for Cross-Sectional Studies

Questions for Cross-Sectional Studies	Becker and Sempick (2018)	Cassidy, Giles and McLaughlin (2014)	Collins and Bayless (2013)	Nagl-Cupal et al. (2014)	Warren (2007)
1) Were the criteria for inclusion in the sample clearly defined?	2	2	2	2	2
2) Were the study subjects and the setting described in detail?	2	2	2	2	2
3) Was the exposure measured in a valid and reliable way?	2	2	2	2	2
4) Were objective, standard criteria used for measurement of the condition?	2	2	2	1	2
5) Were confounding factors identified?	2	N/C	2	N/C	2
6) Were strategies to deal with confounding factors stated?	1	N/C	2	N/C	1
7) Were the outcomes measured in a valid and reliable way?	2	2	2	2	2
8) Was appropriate statistical analysis used?	2	2	2	2	2
Overall appraisal: Include (Inc) or Exclude (Exc)	Inc	Inc	Inc	Inc	Inc

Chapter Two

Integrative Literature Review

2.1 Introduction

The previous chapter considered the difficulties and challenges young carers can experience as a consequence of their caring role. A literature review was conducted to explore the impact of caring on a young person's health and social wellbeing, and key legislation pertaining to identifying and supporting young carers through assessment was discussed. This chapter considers assessments further, by investigating which tools, if any, are used to aid professionals in their statutory duties. According to Streiner, Norman and Cairney (2015), there is often a paradoxical situation in the field of health and wellbeing measurement tools, in that there can simultaneously be too many and not enough appropriate tools to use. Therefore, before embarking on developing another, it was important to critically review and appraise existing screening and assessment tools created specifically for use with young carers, to identify if a new tool was indeed required. The chapter concludes with information received from a variety of young carers organisations nationally, that supports and strengthens the rationale for developing a new screening tool.

2.2 An Integrative Review of Existing Screening and Assessment Tools

In order to establish the types of screening and assessment tools currently used by professionals working with young carers, a review of literature surrounding them was conducted to address the following question:

> '*What tools have been developed to screen or assess young carers for any needs they may have as a result of their caring role?*'

An integrative review was chosen as it can include literature from qualitative and quantitative research studies and theoretical sources, and adopts a critical and systematic approach (Whittemore and Knafl, 2005).

2.3 Search Strategy

An initial search strategy was created in November 2016, and a further search of the literature was undertaken in March 2019. Titles and abstracts of studies from the electronic databases: CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed, Academic Search Premier (EBSCO) and PsycINFO were searched as these were deemed most relevant to the topics of health and social care. The inclusion criteria for the searches were to include studies of tools developed to screen or assess young carers needs undertaken during the last 26 years (1993 – present), as this is the approximate period of time from when research involving young carers began (Aldridge and Becker, 1993; Leu and Becker, 2014). Further restrictions were to include literature published in the English language only, as the costs of translation were not feasible for this study. Table 7 below displays the inclusion and exclusion criteria for papers to be reviewed.

Table 7: Inclusion and Exclusion Criteria

Inclusion Criteria:	**Exclusion Criteria:**
Conducted between 1993 – present	Studies not meeting the inclusion criteria
Written in English language	Secondary or policy reviews
Studies investigating tools developed to screen or assess young carers' needs	Studies from countries that are culturally very different to UK
Empirical studies	

Key words and terms were used separately and then in combination with Boolean operators applied, where necessary, for a more focused search. Key terms included: "young carer*" OR "young caregiver*"; "assessment" OR "measure" OR "screening"; "assessment of need*" OR "needs assessment" OR "assess* need*"; and "assessment tool*" OR "measur* tool*" OR "screen* tool*". The results are depicted in Table 8 on the following page.

Table 8: Number of Hits Across Databases (March 2019)

	Search Terms	PubMed	CINAHL	Academic Search Premier	PsycInfo
1	"young carer*" OR "young caregiver*"	13	90	177	138
2	"assessment" OR "measure" OR "screening"	1,577,699	325,722	1,027,666	475,485
3	"assessment of need*" OR "needs assessment" OR "assess* need*"	4,926	3,226	4,534	5,678
4	"assessment tool*" OR "measur* tool" OR "screen* tool*"	25,604	14,078	21,970	14,587
5	1 & 2	3	10	14	20
6	3 & 5	0	0	0	3
7	4 & 5	0	2	0	1

Further searches were undertaken by hand searching the reference lists of the selected studies. Additional searches for grey literature were conducted via Google Scholar and Edge Hill University's (EHU) Discover More search engine. Search alerts were initiated from ResearchGate, Mendeley and Google Scholar, and the Cochrane Library was also searched, although this did not yield any results. Duplicates and papers not meeting the inclusion criteria were screened and removed. One study was kept following screening, despite having a paucity of information about the development of the identification and screening tool it referred to. Contact was made with the study's author who clarified that the tool had been developed based on the literature rather than empirical research; no additional information about its development was available. Another study also referred to a tool that was developed based on existing literature rather than empirical research, however this study contained some information about its development. After discussion with the supervisory team, it was decided that these studies should be included in the review, as they met the criteria of being developed for use with young carers. A flow diagram of the study selection process, adapted from PRISMA (Moher et al. 2009), is set out in Figure 3 on the following page.

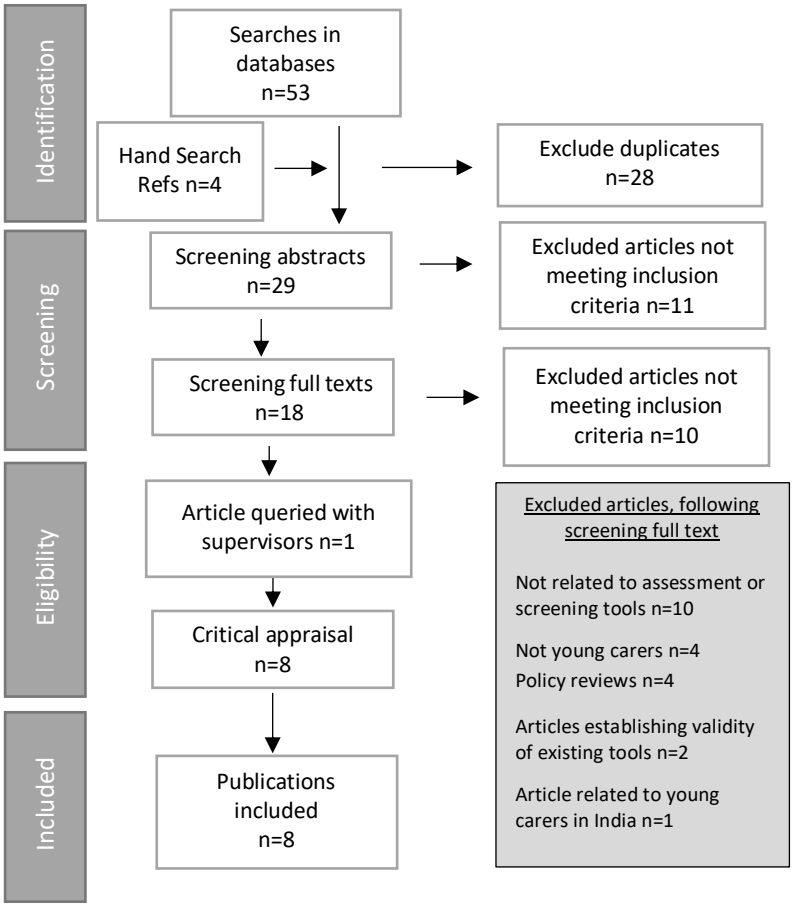


Figure 3: Adapted PRISMA flow diagram of study selection process for literature review of tools

2.4 Methods of Quality Appraisal for Eligible Studies

All eight of the eligible studies were read in full. The six empirical studies were methodically assessed using the Mixed Methods Appraisal Tool (MMAT) as a framework to critically assess their thoroughness (Pluye et al. 2009, 2011). This appraisal tool was selected as it is a validated and reliable tool for the assessment of mixed methods studies for inclusion in a review, i.e., reviews that include qualitative, quantitative and mixed methods studies, but not reviews or theoretical studies (Pace et al. 2012; Souto et al. 2015). It was not used to exclude articles according to quality, but to investigate and interrogate them systematically (Pluye et al. 2009, 2011). As Kuper, Lingard and Levison (2008) suggest, thorough assessment is an interpretative act that requires informed reflection, therefore content and relevance were a key consideration when considering scoring the studies for inclusion.

The scoring system used for the MMAT is based on answering 'Yes', 'No', 'Unclear' or 'N/A' (not appropriate) to each of the questions contained within the relevant sections, dependent on how comprehensively the question was addressed. Each section contains a series of questions, and the appraisal score is calculated as a percentage of the number of 'Yes' responses met within each section, divided by the number of questions in that section, i.e. one 'Yes' response from a section containing four questions = 25%; two 'Yes' responses from a section containing three questions = 66%, etc. (Pluye et al. 2011). The 'Yes' responses are then divided by the total number of questions from all of the applicable sections to give an overall appraisal score. Using this system resulted in scores ranging from 75% to 82% for each of the studies reviewed, indicating that the overall thoroughness was good (Pluye et al. 2011). As noted earlier, two of the studies were not empirical, therefore, they were not appraised using the MMAT but through discussion with the supervisory team. Results from the appraisal are displayed in Table 12 at the end of this chapter.

2.5 Overview of Included Literature

None of the studies reviewed were excluded following appraisal, as all appeared valuable to aid understanding of how any needs young carers may have arising from their caring role could be identified, screened for and/or assessed. The included literature consisted of eight studies, reporting on nine tools in total as two of the tools were developed within the same study. An overview and summary of the eight studies, containing relevant demographic information, aims, methodology, key findings, outcomes, and quality appraisal scores is presented in Table 11 on the following pages.

For ease of reference, acronyms of the nine tools reviewed in the eight studies are listed first in Table 9, together with Table 10 of additional acronyms used in the overview Table 11.

Table 9: Tool Acronyms used in Table 11 (Summary of Studies)

Tool	Author(s) (Country)	Full Title
CCDRH	Gaffney (2007) (New Zealand)	Children's Caring and Domestic Role at Home
MACA-YC18	Joseph et al. (2009) (UK)	Multidimensional Assessment of Caring Activities Checklist
OCINI	Nicholls et al. (2016) (UK)	Offspring Chronic Illness Needs Instrument
OCNI	Patterson, Pearce & Slawitschka (2011) (Australia)	Offspring Cancer Needs Instrument
PANOC-YC20	Joseph et al. (2009) (UK)	Positive and Negative Outcomes of Caring Questionnaire
YACS	Ireland & Pakenham (2010) (Australia)	Youth Activities of Caregiving Scale
YCPSS	Earley, Cushway & Cassidy (2006) (UK)	Young Carers Perceived Stress Scale
YCOPI (& YCOPI-Revised)	Pakenham et al. (2006) Cox & Pakenham (2014) (Australia)	Young Carers of Parents Inventory Revised version of the Young Carers of Parents Inventory
YC-QST-20	Aldridge (2014) (UK)	Young Carer Screening Tool and Questionnaire

Table 10: Additional Acronyms used in Table 11 (Summary of Studies)

Acronym	Author(s)	Full Title
AC-QoL	Elwick et al. (2010)	Adult-Carers Quality of Life Scale
ACS	Frydenberg & Lewis (1990)	Adolescent Coping Scale
BDS-RS	Birleson (1981)	Birleson Depression Self-Rating Scale
DASS-21	Henry & Crawford (2005)	Depression Anxiety Stress Scale -21 (Short Version)
GHQ	Goldberg (1978)	General Health Questionnaire
PSSS	Procidano & Heller (1983)	Perceived Social Support Scale
SDQ	Goodman, Meltzer & Bailey (1998)	Strengths and Difficulties Questionnaire

Table 11: Summary of Studies in the Integrative Review

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Gaffney (2007) **CCDRH**	To develop a recording tool for social services agencies to use in order to identify young carers	Tool developed from existing UK and Australian literature, then adapted after consulting with unspecified number of staff at agencies who had agreed to pilot it. Professionals (n=15) working at 4 agencies piloted tool after development.	No information on study design Each agency asked how they conducted assessment, how the tool might fit within their organisations, and their experiences of using it. No information given about reliability or validity measures, other than researcher noted reliability addressed by asking agencies to evaluate format and questions in the tool before it was used	All 4 agencies had difficulties using the tool and had to adapt it to suit themselves 21 children aged 7-14 were identified as possible young carers, out of 495 visited over 12 month period - between 1-15% for each agency 9 identified as definite young carers: Male=3; Female=6 Care recipients: Parents=7 Sibling=1 Grandparent=1 Agencies were reluctant to risk compromising relationships with families in order to collect data Using tool with families already known to social services for other complex issues made it difficult to separate young carers' roles and potential impact from other areas	CCDRH tool developed with 25 items to try to aid social services agencies in identifying hidden young carers	N/A

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Joseph et al. (2009)	1) To develop two scales for use with young people:	410 young carers aged 6.5-22, recruited via carers database (34% response rate) Male = 142 Female = 268 Care recipients not reported	Quantitative Study Design Research team (n=4) discussed item inclusion and also used feedback from young carer groups to develop initial questionnaires	Principal components analysis produced 18 items from 6 components: domestic tasks; household management; personal care; emotional care; sibling care and financial/practical care	MACA-YC18 developed with 18 items to measure time spent on caring activities	75%
MACA-YC18	A) A checklist of the total amount of caring activities undertaken (MACA-YC18)		Initial questionnaire had 42 items			
PANOC-YC20	B) A measure of psychological outcomes related to caring (PANOC-YC18)		Initial questionnaire had 75 items	Principal components analysis produced 20 items from 2 components: positive outcomes and negative outcomes	PANOC-YC20 developed with 20 items to measure positive & negative outcomes of caring	
	2) To validate study by obtaining preliminary normative data for both tools	124 young carers aged 8-21, recruited from projects not involved in earlier development (35% response) Male = 40 Female = 84	New MACA-YC18 and PANOC-YC20 tools administered by young carers project staff, together with BDS-RS to test convergent validity	Correlations for MACA-YC18 reported by gender: Female = higher scores were related to negative outcomes Male = higher scores related to positive outcomes Scores on PANOC-YC20 correlated with scores on BDS-RS, indicating convergent validity		

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Patterson Pearce & Slawitschka (2011) **OCNI**	To develop a tool to measure unmet psychosocial needs of young people who have a parent with cancer	1) 14 young people aged 12-22, recruited through CanTeen, an Australian organisation for young people affected by cancer: Male = 6 Female = 8 (22% response rate) Care recipients = parents 26 Staff members: Male = 6 Female = 20 (46% response rate)	Mixed methods study design 1) Qualitative data from focus group (n=6) and semi-structured telephone interviews (n=8) with young people Quantitative data from staff survey questionnaire (n=26)	1) Triangulation of thematically analysed qualitative data with quantitative data produced 67 items from 8 domains	OCNI developed with 67 items to measure unmet psychosocial needs of young people who have a parent with cancer	82%
		2) 116 young people aged 12-24, recruited via CanTeen, as above Male = 39 Female = 77 (30% response rate) Care recipients = parents	67 item questionnaire completed either online (n=19) or by post (n=97), together with either the SDQ (for those aged 12-17); or DASS-21 (for those aged 18-24)	2) 90% of participants had 10 or more needs arising from their caring role, and 87% of them had at least one unmet need. High positive correlation found between number of unmet needs and adverse mental health scores in the SDQ and DASS-21.	(Later reduced to 45 items following pilot study involving 256 young people (Patterson, 2013). This confirmed internal consistency for domains was good to excellent	

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Nicholls et al. (2016) **OCINI**	1) To determine if cancer literature re young carers is generalisable to other chronic long-term conditions	1) 7 young carers aged 17-19 Male = 2 Female = 5 (response rate n/a as this was an opportunistic sample obtained from colleagues) Care recipients were parents	Mixed Methods Study Design 1) Qualitative data obtained from unstructured interviews and thematically analysed using interpretative phenomenological analysis	1) Analysis found the OCNI could be adapted and tested for suitability to measure unmet needs for young people who have a parent with a chronic condition	OCINI developed with 26 items to measure psychosocial needs of young adult carers of parents with a chronic long-term condition	82%
	2) To develop a screening tool based on the OCNI	2) 107 young carers aged 17-19 Male = 34 Female = 73 (63% response rate) Care recipients were parents	2) Questionnaires completed then quantitatively analysed to determine factor structure, reliability and validity. Comparisons made with the DASS-21 and AC-QoL	2) Significant and positive correlations found between unmet needs and stress, anxiety and depression; inversely with quality of life and time since diagnosis		

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Ireland & Pakenham (2010) **YACS**	To develop a scale of care tasks performed by young carers	135 carers aged 10-25, recruited from carer associations & a young carers camp in Australia Male = 54 Female = 81 (response rate reported as unknown, due to varied recruitment methods) Care recipients: Parent = 98 Sibling = 37	Quantitative Study Design 1) Questionnaire developed from literature review and feedback from consultation group of young carers (n=5) Initial item pool sent to researchers for feedback on content & readability 2) Packs containing new YACS tool & demographic questionnaire sent by post or email to participants 3) Comparisons made with YCOPI to test convergent validity	Findings suggest correlations between increasing care tasks and age of young carer, and between young carers in single parent households performing more tasks than those in dual parent households There were significant differences between whether care recipient had a physical or mental illness/disability 3) Convergent validity significant, except for caregiving discomfort, suggesting care tasks per se are not a source of carer discomfort	YACS developed with 28 items to measure the type of care tasks performed, and to aid further theoretical development about young carers	75%

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Earley, Cushway & Cassidy (2006) **YCPSS**	To develop a measure of the demands of the caregiving role on young carers	108 participants aged 12-18, recruited from young carer groups Male = 46 Female = 62 (50% response rate) Care recipients: Parent = 67 Sibling = 30 Grandparent = 3 More than one family member=8	Quantitative study design 1) Findings from analysis of data from earlier study involving 17 young carers aged 10-16, in two focus groups, used to generate 50 items for inclusion in a questionnaire 2) Questionnaires completed in groups of 5-10 young carers. Feedback collected, and comparisons made with PSSS, ACS & GHQ	Overall correlations with perceived psychological distress and higher burden of care were significant (Further exploration of YCPSS by Cassidy and Giles (2013) identified a benefit finding dimension for young carers)	YCPSS developed with 31 items to measure stress experienced by young carers as a result of their caring role	75%

Author(s) (year) Tool	Study Aim	Sample	Design & Methodology	Main Findings	Outcomes	Quality Appraisal Score
Pakenham et al. (2006) **YCOPI**	To develop an inventory that measures the psychosocial impact of caring on young people, and compare outcomes with young non-carers	245 participants aged 10-25, recruited from schools, university, support groups & general community 100 young carers: Male = 28 Female = 72 (response rate not known) Care recipients were all parents 145 young non-carers: Male = 48 Female = 97 (response rate not known)	Quantitative Study Design 1) Findings from thematic analysis of qualitative data from earlier study (n= 7) of participants aged 9-35 to formulate questionnaire with 35 items 2) Age appropriate questionnaires (10-13; 14-25) completed by both groups for comparison. Construct validity tested by comparing with stress and coping theory by Lazarus and Folkman (1984)	8 factors described diverse impacts from caring. Compared with non-carers, young carers reported higher levels of caregiving impact, less reliance on problem-solving coping, and higher somatisation and lower life satisfaction. (Further exploration of the YCOPI by Cox and Pakenham (2014) found an additional dimension – young carers need for information about their parent's medical condition, resulting in the YCOPI-Revised)	YCOPI developed with 48 items to measure the psychological impact of caring on young carers	75%
Aldridge (2014) **YC-QST-20**	To help researchers and health & social care professionals identify children who are providing care for a relative	N/A	No information on study design Tool developed from existing literature gathered over previous 20 years	Once young caring has been identified using the YC-QST-20, author recommends other (unnamed) tools/measures are used to ascertain the extent and impact of caring	YC-QST-20 developed with 20 items (& 11 extra questions, dependent on answers) to identify young carers	N/A

2.6 Review Findings

One of the advantages of an integrative synthesis is that the focus is on summarising data, and the variables or concepts under which the data are to be summarised are assumed to be largely well specified and secure (Dixon-Woods et al. 2005). Therefore, the following sections summarise and consider findings from data extracted from the studies reviewed, focusing on the sample, methods, and validity and reliability of the studies. Details are then given of a brief scoping review conducted with professionals working with young carers, about the tools they currently use.

2.6.1 Demographic Details of the Included Studies

Three of the tools were developed in Australia (OCNI, YACS, YCOPI), one in New Zealand (CCDRH) and the remaining five in the UK (MACA-YC18, OCINI, PANOC-YC20, YCPSS and YC-QST-20). As previously stated, the CCDRH and YC-QST-20 were not developed empirically, however sample sizes for the development of the other seven tools ranged from 107 to 410, with a median level of 204 participants. All of the empirical studies were conducted using young carers as the participants (Earley, Cushway and Cassidy, 2006; Pakenham et al. 2006; Joseph et al. 2009; Ireland and Pakenham, 2010; Patterson, Pearce and Slawitschka, 2011; Nicholls et al. 2016), although the sample used in the development of the YCOPI also included a non-caring control group for comparison.

All of the empirical studies noted the young carers' relationship to the care recipients, with the exception of the study by Joseph et al. (2009). Two of the studies noted the types of illnesses and disabilities experienced by the care recipients, together with information about co-morbidities, length of time caring and presence of other family members, as the authors felt these factors could affect the care tasks young carers engage in (Pakenham et al. 2006; Ireland and Pakenham, 2010). Only one study focused on young carers of people living with a particular illness (Patterson, Pearce and Slawitschka, 2011). However, the study by Earley, Cushway and Cassidy (2006) reported they had excluded young carers of people with mental health difficulties, drug or alcohol related problems, or HIV/AIDS.

2.6.2 Ethics, Data Collection and Analysis of the Included Studies

All of the empirical studies in this review provided information about the research ethics committees or institutional review boards that granted approval prior to their commencement. Two of the tools, the OCINI and OCNI, were developed using mixed method studies that began with interviews, before further phases of quantitative data collection utilising questionnaires were conducted (Nicholls et al. 2016; Patterson, Pearce and Slawitschka, 2011). Additionally, the authors of two of the studies, the YCPSS and YCOPI, reported using findings from earlier qualitative studies to generate items for the questionnaires in their studies (Earley, Cushway and Cassidy, 2006; Pakenham et al. 2006). Questionnaires were also used to collect data for analysis and formation of the items in the MACA-YC18 and PANOC-YC20 (Joseph et al. 2009). Similarly, a questionnaire was used to collect data by Ireland and Pakenham (2010), who also consulted with young carers and professionals to obtain feedback on items to be included in the YACS. All of the studies additionally utilised data collected from existing literature, however this was reported to be the only method used to drive development of the YC-QST-20 (Aldridge, 2014) and the predominant method used to develop the CCDRH (Gaffney, 2007).

2.6.3 Validity and Reliability of the Included Studies

Establishing validity is an important factor in demonstrating whether an instrument achieves what it is meant to achieve (McDowell, 2006; Streiner, Norman and Cairney, 2015). Various approaches can be used to try to establish validity including assessing a combination of the face, content, criterion or construct validity of each instrument (Streiner, Norman and Cairney, 2015). Reliability relates to the ability to achieve similar results with repeated measures and is usually established by performing a test-retest analysis (Abell and Kamata, 2009). This examines the variability associated with repeated measurements of the same phenomena, at different points in time. Each of the studies reviewed, apart from the YC-QST-20 (Aldridge, 2014), used various methods to try to establish validity and reliability and these are considered in turn.

CCDRH: No information was given about validity or reliability testing measures for the CCDRH, other than the researcher suggested reliability was addressed by asking agencies to evaluate the format and questions in the tool before it was used (Gaffney, 2007). Furthermore, the author indicated difficulties in engaging agencies to use the tool, as the types of agencies who participated in the study were involved with families experiencing complex difficulties.

MACA-YC18 and PANOC-YC20: The initial 42 items on the MACA-YC18 were subject to principal components analysis, resulting in six factors: personal care; domestic tasks; emotional care; household management; sibling care; and financial/practical help (Joseph et al. 2009). Analysis of the initial 75 items on the PANOC-YC20 resulted in two principal components: positive outcomes and negative outcomes. Following statistical analysis, each tool was reduced in length to 18 items for the MACA-YC18, and 20 items for the PANOC-YC20. Both tools were then validated in a further study using 124 participants aged 8-21. In order to test for convergent validity of the PANOC-YC20, the Birleson Depression Self-Rating Scale (BDS-RS) was used (Birleson, 1981). To test convergent validity of the MACA-YC18, two extra questions were included relating to time spent on caring tasks, and two extra questions were included relating to times late or missing from school. Correlations between the MACA-YC18 and PANOC-YC20 found that for girls, emotional care and household management were perceived as negative, whilst conversely emotional care was also perceived as positive. However, for boys, financial/practical help, domestic chores and looking after siblings were perceived positively, whilst personal care tasks were perceived negatively. Although preliminary normative and convergent data were presented, reliability measures were not given.

OCNI: Triangulation of thematically analysed qualitative data yielded eight domains from 67 items, with internal consistency reaching an acceptable level (0.64 - 0.92), as assessed using Cronbach's alpha (Patterson, Pearce and Slawitschka, 2001). Unmet needs concerning support from peers, a supportive education environment, access to information and dealing with feelings were the most frequently represented domains. Correlations between unmet

needs and scores in the Strengths and Difficulties Questionnaire (SDQ) (Goodman, Meltzer and Bailey, 1998) and Depression Anxiety Stress Scale – 21 (Short Version) (DASS-21) (Henry and Crawford, 2005), revealed 50% (58) of participants had scores placing them in the at risk/clinically elevated ranges for adverse mental health. Face and content validity were assessed to be acceptable, via subjective feedback and analysis by three assessors. Construct validity and test-retest reliability were not assessed in this study; however, they were established in a further pilot study that looked at the psychometric properties of the OCNI (Patterson et al. 2013). The pilot study involved 256 young people aged 12-24 and exploratory factor analysis and Rasch analysis were used (Patterson et al. 2013). Construct validity was determined by correlations between psychological distress, which was measured using the Kessler 10 psychological distress tool (Kessler et al. 2003) and the OCNI domains. Internal consistency for domains was reported as good to excellent, with the lowest domain Cronbach's alpha being 0.89. Reliability was measured by looking at test-retest correlation co-efficients (Abell and Kamata, 2009), which was reported to be 0.73 overall at questionnaire level, indicating good reliability.

OCINI: When performing factor analysis, McDowell (2006) argues that the number of participants in a sample should be at least five times the number of items in the measure being analysed. However, despite having a lower ratio than this in the development of the OCINI, Nicholls et al. (2016) noted that as principal axis factor analysis was 96.9% accurate for Rouquette and Fallisard (2011) when a sample of 100 was used to analyse 45 items, this was used as a guide for their study. The five subscales in the OCINI correlated inversely with quality of life and time since diagnosis and positively with stress, anxiety and depression. This indicated higher needs were associated with poorer outcomes and a shorter time since diagnosis and concurred with similar correlations identified in the development of the original OCNI, suggesting construct validity of the subscales. Confirmatory factor analysis was not undertaken, and the researchers noted that although initial validation of the OCINI was conducted in the UK with 17-19 year olds, the development of the original OCNI was conducted in Australia with a younger sample, which could have resulted in different factors being identified in the analysis.

YACS: The 28 items on the YACS were subject to principal components factor analysis, yielding four factors: instrumental care; social/emotional care; personal/intimate care; and domestic/household care. Inter-factor correlations amongst the factors were all reported to be positive and significant, indicating acceptable homogeneity of the items. The developers of the YACS then used comparisons with the YCOPI (Pakenham et al. 2006) and the SDQ (Goodman, Meltzer and Bailey, 1998), to test convergent and criterion validity. Strong positive correlations between the YACS and the YCOPI provided good convergent and thereby construct validity data for the YACS. Criterion validity suggested that higher levels of care tasks were related to more adverse experiences (e.g. emotional distress, activity restrictions), but conversely also to greater levels of prosocial behaviour (e.g. perceived maturity, caregiving confidence), indicating a juxtaposition between both negative and positive outcomes. Further research with respect to test-retest reliability and validation of the factor structure was suggested by the researchers.

YCPSS: Principal component analysis was performed on an initial 50 items in the YCPSS, resulting in five factors: devaluation of role; personal value of role; overload; social restrictions; and family cohesion (Earley, Cushway and Cassidy, 2006). Those factors were then tested against the Perceived Social Support Scale (PSSS) (Procidano and Heller, 1983), the Adolescent Coping Scale (ACS) (Frydenberg and Lewis, 1990) and the General Health Questionnaire (GHQ) (Goldberg, 1978). The overall YCPSS score correlated significantly with perceived psychological distress, burden of care, and avoidance coping. A further study exploring a benefit finding factor in the YCPSS, revised the dimension of the YCPSS with the permission of the original researchers (Cassidy and Giles, 2013). A further factor was added, and the six factors were renamed: perceived role stress; benefit finding; school impact; social impact; family impact; and social recognition of the role. Internal consistency was described as good, with significant correlations with other factors from the YCPSS. Concurrent validity was demonstrated by the strong positive correlations with family and friends support and problem focused coping.

YCOPI: Construct validity of the YCOPI was tested by examining the relationship between the scale and other theoretically relevant stress and coping variables (Pakenham et al. 2006). Factor analysis was performed on 48 items, resulting in eight reliable factors. Comparisons were made between two groups, young carers and non-carers, and the former were found to have higher somatisation and lower life satisfaction than the non-carers. Inter-correlations between the factors were reported to be significant and positive. A further study of the YCOPI tested factor structure and measurement invariance and an additional factor was added, relating to young carers' need for information about their family member's medical condition, resulting in the YCOPI-Revised (Cox and Pakenham, 2014).

2.7 Strengths of the Included Studies

All of the tools reviewed have usefulness for the purposes they were designed to address, and some have particular strengths. The MACA-YC18 and PANOC-YC20 were developed psychometrically, using a relatively large sample size of 410. This enabled the researchers to identify gendered differences in caring outcomes: girls reported more negative outcomes; boys reported more positive outcomes. This is an area that is currently under-researched (Chikhradze, Knect and Metzing, 2017), but is important to consider in order to prevent girls from feeling obliged to take up 'early caregiving careers' (Nagl-Cupal et al. 2014:2322). The researchers who developed the MACA-YC18 and PANOC-YC20 suggest the tools could also be useful in understanding more about the psychological effects of caring, and for evaluating intervention strategies used by young carer organisations (Joseph et al. 2009). In a further study by Joseph, Becker and Becker (2012), the authors suggest the PANOC-YC20 is particularly useful for identifying whether support following assessment has resulted in a reduction of negative outcomes and an increase in positive ones.

Although the CCDRH was developed to aid identification of young carers by social services agencies already working with vulnerable families, the YC-QST-20 is the only tool in the review that helps identify hidden young carers. This could be useful for school or health care professionals who work with young people not previously known to be caring for a family member (Aldridge, 2014). This is particularly relevant following the introduction and

implementation of the Care Act (2014) and the Children and Families Act (2014), as discussed in the previous chapter, as these Acts place new duties on professionals to identify young carers. Although the YC-QST-20 was not designed to ascertain the impact of caring, it could be used by organisations to generate statistical data on the prevalence of young carers to support policy directives and service delivery initiatives. This latter point was highlighted as particularly pertinent in a recent policy review that discusses the effects of economic restraints and cuts to funding for youth services (Aldridge, 2017).

2.8 Limitations of the Included Studies

There are also some limitations to note from the studies reviewed. The MACA-YC18 measures the amount of caring activity undertaken by young carers, but some of the questions it asks are ambiguous, such as asking young carers how often they clean their own bedroom, or wash dishes, which could be seen as normal family activities unrelated to caring (Kavanaugh et al. 2015). Equally, 'taking siblings to school' may be pragmatically convenient and not related to being a young carer, and 'working part time' could again be viewed as normal late adolescent activity (Joseph et al. 2009:520). Furthermore, as highlighted by Gaffney (2007), the time spent on a caring activity does not necessarily equate to its importance, e.g. giving a parent medication may not take very long but could have serious consequences if not carried out correctly (Royal College of General Practitioners (RCGP), 2011). The PANOC-YC20 also contains ambiguous statements that young carers are asked to quantify, with one in particular being very subjective, asking young carers to rate: 'Because of caring my parents are proud of the kind of person I am' (Joseph et al. 2009:520).

Although research has indicated that the needs of young carers in developed countries are very similar (Becker, 2007), the CCDRH was developed primarily to try and identify young carers in families already known to social services agencies in one region in New Zealand. Furthermore, it was created from existing UK and Australian literature and through discussions with an unspecified number of staff at the agencies who agreed to pilot it, with no information about validity or reliability measures conducted. The OCNI was developed to measure the unmet psychosocial needs of young people who have a parent with cancer, but

this does not necessarily equate with them being young carers. Furthermore, by definition, it excludes young people who care for siblings, grandparents or any other family members. The study for the OCINI only used participants aged 17-19 and therefore is not representative of many young carers. The developers of the YCOPI used data from a very broad age range of participants, from ages 9-35, to inform the items in their scale. This is unlikely to be representative of the majority of young carers, as clearly the needs of young carers and young adult carers at the two extremes of the scale will be conceivably different. Indeed, all of the empirically developed tools reviewed, except the OCINI and YCPSS, utilised data from young carers spanning a very broad age range. However, although the sample involved in the development of the YCPSS had a narrower age range, it was restricted to exclude young carers of family members with mental health issues, or drug or alcohol related conditions. Again, this is unlikely to be representative of all young carers, as highlighted in the previous chapter.

None of the tools reviewed offer signposting or suggestions for possible further assessments, actions or interventions. Moreover, none of the studies reviewed reported how long it took, or was likely to take, to administer the tools once developed. However, anecdotal information by staff at a large national children's charity in Lancashire, who frequently use the MACA-YC18 and PANOC-YC20 concurrently to assess young carers, suggested it can take in excess of two hours to administer those particular tools. Moreover, the Carers Trust (2016b) highlight how following the changes in legislation, discussed in the previous chapter, increased awareness of young carers has resulted in more of them being identified and referred for assessment. This has presented a challenge for some local authorities and services to cope with, with some needing to employ waiting lists for assessments as a result (Carers Trust, 2016b).

Therefore, in order to understand more about the screening and assessment processes commonly used with young carers, a brief scoping exercise was undertaken with professionals from a variety of national young carers' organisations. As discussed in the previous chapter, some local authorities undertake the assessments themselves, and some outsource them to be undertaken by charities and third sector organisations.

2.9 Brief Scoping Exercise

Representatives from young carers organisations in Liverpool, Surrey, Oxfordshire, Northamptonshire and Dorset who were attending a large national practitioners' event in Manchester, organised by the Carers Trust, were approached and invited to take part in a consultation about their experiences of assessment processes in February 2018. This was an opportunistic sample from approximately 30 representatives from young carers organisations present. Each representative who took part in the consultation revealed their organisations followed different procedures on receipt of a referral for assessment, and none used the aforementioned tools for screening purposes. However, one organisation used the MACA-YC18 and PANOC-YC20 as part of the full assessment process, which they reported could take several hours to conduct as assessments were carried out in two parts; one part at home, and the other in school. In some organisations, referrals were added to a waiting list and seen chronologically; in others they were screened for assessment using forms created locally themselves. These forms and procedures are discussed in turn.

The representative from Liverpool reported they use a form called the Early Help Assessment Tool (EHAT) that was developed locally by the Local Authority, and is based on items in the Common Assessment Framework (Department for Education and Skills, 2007) for children and young people. The EHAT is used by various local organisations and agencies working with children, young people and families in Liverpool, and not just those working with young carers. This allows information to be shared electronically between specialist services, so they can ensure locally responsive solutions are used to address issues, and resources are targeted to families accordingly based on identified need.

The representative from Surrey reported their organisation developed two assessment tools locally: 'About Me' for use with primary school aged children; and 'i-Care' for use with secondary school aged children. The former is a visual tool that can be used to explore wishes and worries with young carers under the age of 11, and the latter is a 12 page booklet that young carers aged 11-18 are encouraged to complete themselves. However, they did not have

a screening process and young carers were assessed for needs chronologically from when they were referred. In Oxfordshire, the assessment process involves asking relevant questions from two different tools within the Outcomes Star™ family of assessment and evaluation tools. There is no tool specifically developed for use with young carers within the Outcomes Star™ family, so a hybrid was created by staff in the organisation from the generic My Star™ tool for use with vulnerable children and young people, and the Carers Star™, which was developed for use with adult carers.

Similarly, Northamptonshire's young carers' services created their own screening tool by choosing appropriate questions from existing tools in the Outcomes Star™ family, which they have colloquially called the 'Carers Splat'. However, as Joseph, Becker and Becker (2012) highlighted in their study, using generic non-specific measures developed for other groups of people may not be reliable when applied to working with young carers. Finally, the representative from Dorset reported their organisation was unable to find a suitable screening or assessment tool, so developed their own online tool, based on discussions amongst staff.

All of the representatives who took part in the scoping exercise felt a more standardised referral, screening and assessment process would have been useful for them. The key issues highlighted were the lack of consistency between different organisations, both with regards to the tools used and the screening and assessment procedures followed. Moreover, none of the representatives reported their organisations had involved young carers in the development or design of their tools or procedures. Further inconsistencies related to waiting times for assessment, with one organisation confirming it could take in excess of six months from referral to assessment. As highlighted in the previous chapter, many young carers do not recognise their role until it is identified by school staff, social services, or health care professionals involved in the care of their ill or disabled family member. Therefore, it is imperative that once identified, their statutory right for a needs assessment is conducted expeditiously, in order to prevent or minimise any negative impact resulting from the caring

role. Consequently, screening and triaging according to need should be a necessary and important part of the assessment process.

2.10 Summary

In this chapter, nine tools currently used to assess or measure young carers' challenges or needs arising from the impact of caring were reviewed. The studies were undertaken in three different countries, confirming research on young carer difficulties and assessment is an international issue. However, although there are some similarities between findings from studies undertaken in these countries, there are also likely to be some cultural differences. Moreover, each country has their own legislative framework regarding assessing young carers needs. Only three of the empirical studies took place in the UK (Earley, Cushway and Cassidy, 2006; Joseph et al. 2009; Nicholls et al. 2016), with only one of those studies taking place after the implementation of the Care Act (2014) and Children and Families Act (2014). Although there were positive factors in most of the studies reviewed, there were also limitations, particularly regarding the age ranges of the participants, lack of consultation with young carers, and lack of validity and reliability data in some of the studies. It was also evident from the brief scoping exercise that approaches to screening and assessment in the UK can be inconsistent, with long waiting times from referral to assessment in some cases. This has resulted in many organisations that work with young carers having to be creative to find methods and tools that work for them, as there is no national standardised assessment process for young carers (The Children's Society, 2016).

It is suggested, therefore, that current tools lack important elements in helping support young carers, particularly regarding action points and signposting, which a new short screening tool could address. This latter point may be particularly useful for professionals who do not work exclusively with young carers, e.g. school staff, social services and health care practitioners. Furthermore, the new screening triage tool will be developed collaboratively with young carers and professionals, ensuring the items and information it contains are relevant to both groups. A consensus-based approach will be used to select 10 of the most important items, as decided by the groups, thereby providing a quick and expeditious way to screen young

carers for potential areas of burden and triage them accordingly. In the following chapter a research question, together with aims and objectives, is proposed regarding the development of a new short triage tool for use with young carers aged 11-18, of a family member with a long term or progressive illness or disability.

Appendix to Chapter Two

Table 12: Assessment Synopsis Table. Adapted from the Mixed Methods Appraisal Tool (MMAT) v11.

Type of study	Methodological quality criteria	Quantitative (Descriptive)				Mixed Methods	
		Earley, Cushway & Cassidy (2006)	Ireland & Pakenham (2010)	Joseph et al. (2009)	Pakenham et al. (2006)	Nicholls et al. (2016)	Patterson, Pearce & Slawitschka (2011)
Screening questions	Are there clear qual & quant research questions (or objectives*) or a clear mixed-methods question or objective*)?	Yes	Yes	Yes	Yes	Yes	Yes
	Do the collected data address the research question (objective)?	Yes	Yes	Yes	Yes	Yes	Yes
1) Qualitative	**1.1**. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	N/A	N/A	N/A	N/A	Yes	Yes
	1.2. Is the process for analysing qualitative data relevant to address the research question (objective)?	N/A	N/A	N/A	N/A	Yes	Yes
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	N/A	N/A	N/A	N/A	Yes	Yes
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?	N/A	N/A	N/A	N/A	No	No

Type of study	Methodological quality criteria	Quantitative (Descriptive)				Mixed Methods	
		Earley, Cushway & Cassidy (2006)	Ireland & Pakenham (2010)	Joseph et al. (2009)	Pakenham et al. (2006)	Nicholls et al. (2016)	Patterson, Pearce & Slawitschka (2011)
4) Quantitative **	**4.1.** Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Yes	Yes	Yes	Yes	Yes	Yes
	4.2. Is the sample representative of the population under study?	Yes	Yes	Yes	Yes	Yes	Yes
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Yes	Yes	Yes	Yes	Yes	Yes
	4.4. Is there an acceptable response rate (60% or above)?	No (50%)	Unclear	No (34%)	Unclear	Yes (63%)	No (30%)
5) Mixed Methods	**5.1.** Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	N/A	N/A	N/A	N/A	Yes	Yes
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	N/A	N/A	N/A	N/A	Yes	Yes
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?	N/A	N/A	N/A	N/A	Unclear	Yes

2) Quantitative RCTS** and 3) Quantitative non-randomised** categories not included as not relevant to this review

Chapter Three

Methodology Chapter

3.1 Introduction

This chapter presents the study aim and objectives, before considering how a mixed method approach was adopted to address them. As the design of the study required both inductive and deductive approaches, the methodological challenge of how to link the *purpose* of the research with the actual *procedures* used, at a fundamental level will be addressed (Morgan, 2014a; Bryman, 2016). The procedures, or methods, will be discussed in Chapter Four; the purpose of this chapter is to consider the conceptual mixed methodological approach that underpins the research aim and objectives and provides a rationale for the chosen stance. This is an important consideration as '*a researcher's philosophical orientation has implications for every decision made in the research process, including the choice of method*' (Mertens, 2014:7). The chapter concludes by discussing the rationale for choosing the paradigm of pragmatism as a methodology for this study.

3.2 Research Aim

The aim of the study was to explore the experiences of young carers aged 11-18 of a family member who has a progressive or long term illness or disability, and use their views and professionals' views to develop a short screening tool, the Carers' Alert Thermometer for Young Carers, or CAT-YC. The purpose of the tool is to quickly identify and triage any needs arising from the impact of caring and provide signposting for further support, information or interventions, such as a full statutory assessment of needs. In order to ensure that the overall aim was achieved, a range of objectives was necessary.

3.2.1 Research Objectives

1. *To explore the experiences of young carers aged 11-18, and identify factors causing them challenges during their caring experience.*

2. *To seek the views and consensus from young carers and professionals on the items to be included in the CAT-YC.*

3. *To consult with young carers and professionals on the pilot version of the CAT-YC to finalise format, instructions and wording*.

4. *To explore the experiences of young carers and professionals when using the CAT-YC.*

In order to address the aim and objectives above, a mixed method consensus approach undertaken over several phases was implemented. There are many different types of mixed method designs that can be used when conducting research in phases (Johnson, Onwuegbuzie and Turner, 2007; Tashakkori and Teddlie, 2010; Creswell and Creswell, 2017). More than a dozen different mixed method design typologies have been identified in existing studies (Polit and Beck, 2017), but the five main 'families' of mixed method designs are: parallel; sequential; conversion; multi-level; and fully integrated mixed designs (Teddlie and Tashakkori, 2009:151). Additionally, Creswell and Plano Clark (2011:69) cite 'transformative' as a further major design. All of these major mixed method designs feature at least two research strands, with some involving three or more strands.

Parallel mixed designs generally involve two strands, whereby qualitative and quantitative data collection and analysis proceed separately, with little integration (Onwuegbuzie and Leech, 2005). Conversion mixed designs are multi-strand and aim to answer related aspects of the same questions by transforming data so they can be analysed both qualitatively and quantitatively (Teddlie and Tashakkori, 2009). Multi-level mixed designs can be parallel or sequential and are often used for evaluation or programme implementation in which the study extends over time (Creswell and Creswell, 2017). In fully integrated mixed designs, multiple strands run in parallel, but can be complex and difficult for a sole researcher to conduct (Teddlie and Tashakkori, 2009). Transformative mixed designs use social justice theory as a framework and often incorporate parallel, sequential or convergent approaches within them (Creswell, 2015). One of the most popular types, and often used for instrument development, as in this study, is the sequential exploratory mixed method design (Creswell and Plano Clark, 2011, Creswell, 2015; Polit and Beck, 2017). The next section explains the decision taken to follow that particular design for this study.

3.3 Research Design Considerations

The decision to follow a sequential exploratory mixed method design was based on the pragmatic need to use both inductive (exploratory) and deductive (confirmatory) approaches, in order to meet the aims and objectives in each stage of the study (Creswell and Creswell, 2017; Teddlie and Tashakkori, 2009). Furthermore, this type of mixed method design was also used successfully for the development of the original Carers' Alert Thermometer (CAT), which this study draws its development principles from (Knighting et al. 2015, 2016). The original CAT was developed and led by researchers at the Evidence-based Practice Research Centre at Edge Hill University (Knighting et al. 2015, 2016) and was based on the concept of the modified early warning systems (MEWS) used by healthcare professionals, that detects and alerts staff to a patient's need for a higher level of care (Subbe et al. 2001). The CAT was designed to help staff identify and prioritise possible areas of burden or concern for adult carers, both in their caring role and with regard to their own health and well-being.

Throughout the study, although qualitative and quantitative data were collected and analysed in parallel stages at times, the predominant design was sequential, whereby findings from one stage informed the next stage chronologically (Teddlie and Tashakkori, 2009; Polit and Beck, 2017). In the flow chart in Figure 4 on the next page, the basic notational system developed by Morse (1991, 2003) is used to illustrate whether each stage, or phase, was predominantly qualitative (QUAL) or quantitative (QUAN), with uppercase letters used to depict greater dominance and lowercase letters used to depict less dominance. Additionally, [**+**] symbols are used to depict parallel stages and [**↓**] symbols depict sequential stages.

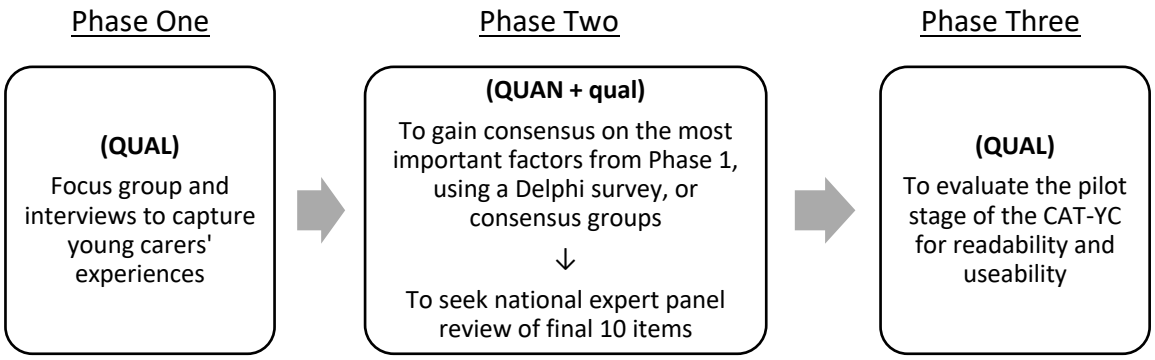


Figure 4: Sequential Exploratory Mixed Method Design

The first phase of the study required a qualitative approach to collect data, as the objective was to explore the experiences of young carers, with the aim of identifying factors they find challenging in their caring role. This helped determine what type and level of support they currently received, if any, and also helped establish whether they had any unmet needs. Data from this phase was used to identify and develop items to form the first round of a modified Delphi survey. The second phase required both qualitative and quantitative approaches, as the objective was to gain consensus on items for inclusion in the CAT-YC. The predominant method used to collect data during this second phase was through the modified Delphi survey from two groups of participants, young carers and professionals, who were asked the same questions in the structured format of a survey (Mertens, 2014; Knighting et al. 2015, 2016). This was completed online by participants aged 16 and above, and at a series of consensus group meetings by younger participants. Following this, a national expert panel reviewed and selected the final items for inclusion. The last phase required a qualitative approach to collect data, as the aim was to explore young carers and professionals' experiences of using the CAT-YC, as part of an evaluation of the pilot stage, and to highlight any potential issues not foreseen in the developmental stage.

The process of administering the Delphi survey will be discussed in detail in Chapter Six, however, there are methodological assumptions related to Delphi surveys that require consideration. First, in order to understand the different methodological underpinnings of qualitative and quantitative research, the ontology (the nature of being or existence), epistemology (the nature of knowledge) and philosophical considerations associated with

them warrants a brief explanation before the methodological assumptions of Delphi surveys are addressed.

3.3.1 Ontology and Epistemology of Qualitative Research

Qualitative research is associated with inductive reasoning, whereby knowledge is seen as subjective and experiences are interpreted in order to construct meaning (Punch, 2005; Green and Thorogood, 2014). Inductive logic is typically employed by qualitative researchers, which involves arguing from the particular to the general, using narrative data to contextualise or categorise phenomena under investigation (Teddlie and Tashakkori, 2009). The ontological assumption is based on constructivism, whereby reality is viewed as socially constructed through shared understandings of phenomena (Plowright, 2011; Bryman, 2016). Data collection and generation is therefore reliant on approaches that are sensitive to the social context within which it is obtained (Topping, 2015; Bryman, 2016). In phase one, this was achieved by using a combination of a focus group and individual interviews, held either at young carers' centres or at participants' family homes. Similarly, in phase three, data collection and generation occurred through individual semi-structured interviews at the same venues. Further details about the methods and processes involved are provided in Chapter Four.

The epistemological assumption associated with qualitative research is that data, interpretation, and outcomes are influenced by the researcher's experiences (Plano Clark and Creswell, 2008). Therefore, a reflective journal was used and maintained throughout the study, in order to facilitate reflexivity. An example extract from the reflective journal is included in Appendix 1 to this thesis. A further concept is confirmability, and this is concerned with establishing that data, findings and interpretation are clearly linked (Lincoln and Guba, 1985; Guba and Lincoln, 1989). Measures were taken at key points in the study to increase confirmability, such as maintaining an accurate audit trail and having samples of data analysed by the supervisory team to establish agreement with the findings (Noble and Smith, 2015; Bryman, 2016; Polit and Beck, 2017). The overall aim was to ultimately produce trustworthy results that are both credible and dependable and can therefore be transferable to other settings (Plano Clark and Creswell, 2008; Bryman, 2016; Polit and Beck, 2017).

3.3.2 Ontology and Epistemology of Quantitative Research

Quantitative research is associated with deductive reasoning, whereby pre-existing theories of knowledge are tested in order to confirm, reject or revise them (Moule and Hek, 2011; Green and Thorogood, 2014). Deductive logic is typically employed by quantitative researchers, which involves arguing from the general to the particular, using statistical analysis of numerical data to test theories or hypotheses (Teddlie and Tashakkori, 2009; Tashakkori and Teddlie, 2010). The ontological assumption associated with quantitative research is based on objectivism, whereby reality is seen as existing regardless of human perceptions of that reality (Plowright, 2011). Therefore, attempts are made in a number of ways (for example through randomisation) to separate the researcher from the participants, in order to maintain objectivity (Topping, 2015; Bryman, 2016). In phase two, objectivity was enhanced by ensuring the sample was representative of young carers and professionals nationally, and participants were recruited from multiple sites (Polit and Beck, 2017). Furthermore, the additional step of recruiting a national expert panel to review and rank the findings, enhanced the study's rigour.

The epistemological assumption associated with quantitative research is that explanations should always be framed in terms of cause and effect, thereby rejecting any notion of purpose (McLeod, 2003; Moule and Hek, 2011). The underpinning principle associated with it is that the world is stable and predictable and by controlling external factors or influences, researchers can minimise bias that might otherwise explain any research findings (Topping, 2015). Bias was minimised in phase two by ensuring the same survey (modified only slightly for ease of readability for younger participants) was used, and data were analysed using the same measures for both (Bryman, 2016; Polit and Beck, 2017). The overall aim was to ultimately produce findings that are both valid and reliable and therefore replicable or generalisable to other settings (Bryman, 2016; Polit and Beck, 2017).

3.3.3 Philosophical Considerations of Qualitative and Quantitative Research

Within both qualitative and quantitative research approaches there are a number of different philosophical positions researchers can take that follow on from these assumptions. If these positions were placed on a spectrum from an externally determined objectivist world view at

one end, to an internally determined constructivist world view at the other, they would be represented as displayed in Figure 5 below:

Objectivism **Constructivism**

(Deductive) **(Inductive)**

Positivism	**Post-positivism**	**Critical Realism**	**Idealism**	**Post-modernism**
Phenomena can be known and studied. Scientific discovery should be value free	External world can be known, but truth is based on probability, not certainty	Phenomena can be estimated by studying its effects	Does not dispute the existence of an external world, but it cannot be objectively known as there are multiple realities	Disputes existence of an external reality, just different versions of different experiences

Figure 5: Ontological and Epistemological Spectrum

Both inductive and deductive approaches were necessary for the development of the CAT-YC, and both have well documented and understood assumptions about their strengths (Creswell and Plano Clark, 2011; Morgan, 2014a). As stated earlier, the decision to follow a sequential exploratory mixed method design was based on the pragmatic need to use both approaches, in order to meet the aims and objectives in each stage of the study (Creswell, 2015; Teddlie and Tashakkori, 2009; Tashakkori and Teddlie, 2010). The aim when conducting mixed method research is not to replace these approaches, but to critically examine and identify which should be used at the appropriate time, and draw from the strengths of either or both as required (Johnson and Onwuegbuzie, 2004; Greene, 2007). As Patton (2002) highlights, this does not require a pledge of allegiance to either approach, rather a recognition that each approach has its own strengths, and these should be considered accordingly. Furthermore, Johnson and Onwuegbuzie (2004) argue that all approaches - qualitative, quantitative and mixed method - are superior under different circumstances, according to the phase of the study. Consequently, taking this pragmatic stance, an inductive approach was taken during the first and last phases, and both inductive and deductive approaches were combined and integrated for the Delphi survey in the second phase (Morgan 2007, 2014b;

Teddlie and Tashakkori, 2009). Philosophical considerations regarding Delphi surveys will be discussed in the next section.

3.3.4 Delphi Survey Consideration and Position

The Delphi survey for this study asked both open and closed questions, and therefore does not ascribe neatly to either an inductive (constructivist) or a deductive (objectivist) ontology (Keeney, Hasson and McKenna, 2011). Some researchers suggest a Delphi survey aligns with a positivist epistemology, as a single statistical measure obtained by converting data collected from open questions into numeric codes that can then be analysed quantitatively, is used to gain consensus (Day and Bobeva, 2005). Furthermore, as the participants strive to agree on the most important factors to include in the CAT-YC, it could be argued this also aligns to a deductive, reductionist approach which adheres to post-positivist principles (Hanafin, 2004).

Other researchers, however, argue a Delphi survey aligns with a constructivist ontology, as data generated are subjective and interpretative (Fitzsimmons and Fitzsimmons, 2001; Amos and Pearse, 2008). During the second phase, each participant drew on their own personal history, social perspective and opinions when answering the questions in the Delphi survey. Furthermore, researchers choose what is important and appropriate to include in a Delphi survey, which inevitably involves some aspects of their own personal history, social perspective and assumptions (Willig, 2001; Morgan, 2007). Moreover, participants had the opportunity to change their position following feedback about the group's opinion, which is more akin to a socially constructed paradigm (Keeney, Hasson and McKenna, 2011).

3.3.5 Integrating Approaches

However, whether Delphi surveys align more with an inductive or deductive approach does not matter if a philosophical stance of pragmatism is taken, because researchers and scholars have repeatedly demonstrated that far from being incommensurable, as was previously considered (e.g. Lincoln and Guba, 2000; Denzin and Lincoln, 2011), it is possible to successfully integrate mixed methods in their studies (Teddlie and Tashakkori, 2009; Tashakkori and Teddlie, 2010; Creswell and Plano Clark, 2011). Furthermore, integrating

approaches within the same phase produced a set of relevant results based on a shared social knowledge that would have been difficult to obtain using a single approach.

However, it is not just during individual phases that approaches can be mixed; as stated earlier, the research study as a whole involved a sequential exploratory mixed method design incorporating a range of approaches. This required a degree of practicality that supports the views of Patton (2002) and Onwuegbuzie and Leech (2005), who suggest that research methodologies are merely tools designed to aid our understanding of the world, and a pragmatic approach should be taken to utilising them. Thus, it could be argued that the appeal for using pragmatism as a methodology was influenced as much by its purpose practically as by its philosophical basis.

3.4 Pragmatic Approach

For the purpose of this study, a pragmatic decision to use all available methods as a legitimate means of addressing the research aim and objectives was taken, and a paradigm of pragmatism was proposed to underpin this decision. Taking a pragmatic approach, however, is not the same as the notion of pragmatism as a philosophical system (Morgan, 2014a). This notion occurred through the relatively recent history of mixed method research, which in turn arose as a consequence of needing to find practical solutions to procedural issues concerning qualitative and quantitative methods within social research (Morgan, 2014b). This resulted in developing what Hall (2013:19) refers to as '*an alternative epistemological paradigm*'. The paradigm of pragmatism has been referred to as a '*philosophical champion*' and leading contender of mixed method research (Greene, 2007:8). It has also been referred to as the third research paradigm by Johnson and Onwuegbuzie (2004), and the third path by Gorad and Taylor (2004).

However, Morgan (2014a:8) argues it should be considered a '*paradigm of choices'* to reflect the complexity of choices required when conducting mixed method research. The following section provides a brief history of how pragmatism evolved, before discussing its philosophy and why it was appropriate as a paradigm for this study.

3.5 Pragmatism

Pragmatism evolved historically from American scholars, such as Charles Sanders Peirce, William James and John Dewey in the early 20th Century, as an alternative philosophical approach to addressing research aims or questions that could not be answered through a solely inductive or deductive paradigm (Morgan, 2007; Tashakkori and Teddlie, 2010). Interestingly, Morgan (2007) suggests the reason why pragmatism was not adopted as a paradigm in its own right sooner, is because early pragmatists held agnostic views of metaphysics, the nature of reality and the possibility of objective truth, and therefore were not taken seriously in the social sciences. Different understandings of pragmatism have been posited: for instance, Peirce approached it from a position of being a creative logician; James offered a pluralistic perspective; and Dewey viewed it as an experimentally oriented and socially conscious approach (Tashakkori and Teddlie, 2010). This latter approach sought to break down the distinction between inductive and deductive paradigms, and focus on the strengths and characteristics of both when addressing research aims or questions. Dewey's opinion was that both paradigms are essentially arguments from two sides of the same coin, i.e. the coin being the research aim or question (Morgan, 2014b). Pragmatism can then be used to address the aim or question by employing the concept of inquiry, which Dewey saw as a process of linking beliefs and actions with decision making. This approach to inquiry involves five steps, as illustrated in Figure 6 below:

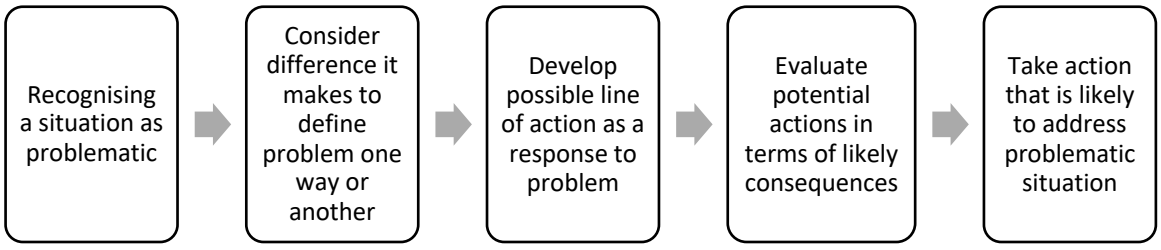


Figure 6: Dewey's Five Step Approach to Problem Solving

This process of inquiry involves an element of speculation about what is *likely* to work, thus requiring ongoing reflection and generating an if-then situation, known as abduction (Morgan, 2014a). If this line of inquiry is applied to the research aim in this study, then it provides an ideal guide for formulating the design of the study. The first step in Dewey's Five Step Approach above involves recognising a situation as problematic. Perhaps 'challenging'

could be considered a more appropriate term than problematic for this study, as the challenging situation was how to implement a consensus approach when developing the CAT-YC. A number of different mixed method designs could have been used to address this challenge, as noted earlier (step two) and each involved careful consideration of the options available (steps three and four), before reaching the decision to develop the sequential exploratory multi-phase design chosen (step five).

Fittingly, Dewey's approach to problem solving through socially conscious inquiry also aligns with Kuhn's (1996) concept of paradigms being social worlds where researchers influence beliefs they consider meaningful and actions they consider appropriate (Morgan, 2014b). This view is not shared by all academics however, and some prefer to focus on the practical application of problem solving. Pragmatism has, for instance, been described by Tashakkori and Teddlie (2009:73) as:

> '*a deconstructive paradigm that debunks concepts such as 'truth' and 'reality' and focuses instead on "what works" as the truth regarding the research questions under investigation. Pragmatism rejects the either/or choices associated with the paradigm wars, advocates for the use of mixed methods in research, and acknowledges that the values of the researcher play a large part in the interpretation of results*'

Some academics regard the '*what works*' definition as a rather crude summary (Morgan, 2014a), and Teddlie and Tashakkori (2010:713) have since refined their description, instead referring to it as '*dialectical pragmatism*', to reflect the importance of qualitative and quantitative approaches within mixed method studies. An additional, and perhaps more comprehensive view of pragmatism is posited by Johnson and Onwuegbuzie (2004) who describe it as a practical way of finding a middle ground between philosophical dogmatism and scepticism based on the following principles in Table 13 on the next page:

Table 13: Characteristics of Pragmatism

a rejection of binary choices such as objectivism v subjectivism
a view of knowledge being both constructed and based on reality
an endorsement of pluralism and eclecticism
a view that inquiry occurs similarly in research and everyday life
a preference for action over philosophising, i.e. endorses practical theory
an endorsement of shared values, such as freedom, democracy, equality and progress
a pragmatic method for making methodological choices

Adapted from Johnson and Onwuegbuzie (2004)

Philosophically, Pratt (2016) argues that pragmatism has the capacity to collapse the distinction between ontology and epistemology, and Morgan (2007) suggests that pragmatism can sidestep ontology by arguing all that is known about reality is that which is discovered through human experience. Thus, this avoids a reductionist view of what is known about the world by acknowledging that there is an external reality, whilst also recognising that perceptual and cognitive functions can shape that reality (Hammersley, 2011).

This is an important philosophical consideration, as a key concept of pragmatism is the belief that human action cannot be separated from past experiences, and the beliefs that have arisen as a consequence of those experiences (Greene, 2007; Morgan, 2014a). Thus, the emphasis for pragmatists is to focus on the nature of shared social experience, rather than the nature of reality. Furthermore, pragmatism replaces previous thinking regarding the differences between approaches, by treating the differences as social contexts for inquiry that will inform social action (Morgan, 2014b). This is referred to by Greene and Hall (2010:132) as '*intersubjectivity*' - whereby we all influence, and are influenced by each other, through a shared responsibility within the world we inhabit. Thus, using pragmatism as a methodological approach is not just a practical or philosophical consideration, but also a socio-political one (Greene, 2007). This position fittingly aligned with the aim and research design of this study, as it sought to explore individual experiences, and use the knowledge gained from the findings to develop a screening tool that can be used in a socially focused context.

The connections between research approaches, ontology and epistemology are perhaps best thought of as tendencies, rather than as definitive positions, for the purposes of this study (Bryman, 2016). Moreover, Powell (2001) argues that for pragmatists, the mandate for science is not about establishing a truth or reality, but to facilitate problem solving in a common-sense way. This resonates with Dewey's assertion that instead of trying to solve traditional philosophical issues, we need to '*get over them*' (Dewey, 1910/2008:14). Consequently, pragmatism places great importance on the research design, as it plays a crucial role in bridging the gap between the research aim and the methods used to address it (Morgan, 2014a). As Miles and Huberman (1984:21) eloquently note: '*epistemological purity doesn't get research done*'. Pragmatic mixed methodology therefore attempts to consider multiple positions, views and perspectives and apply them to the issue at hand (Johnson and Onwuegbuzie, 2004; Johnson, Onwuegbuzie and Turner, 2007).

Pragmatism thus legitimises the mixing of approaches, by focusing on how and why decisions are made, and what the potential impact will be of choosing one method over another (Morgan, 2014b). Consequently, a pragmatic approach informed the sequential exploratory mixed method research design that was utilised for this study. Furthermore, the paradigm of pragmatism is reflected in the research aims and objectives, which sought to identify the unmet needs of young carers aged 11-18 of a family member with a progressive or long-term illness or disability. The implicit assumption was that while individual experiences will differ, there will be shared experiences that will in turn influence the development of the CAT-YC. Moreover, it is likely the CAT-YC will be used by different professionals in various settings, and therefore its development needed to be constructed in the different worlds it seeks to bridge, using a common language that can be understood by all involved.

3.6 Summary

This chapter started with a declaration of the study aim and objectives, before considering how a mixed method approach was required to address them. An explanation of the research design followed, before considering the philosophical issues inherent in mixed method research. It concluded with a rationale for choosing pragmatism as the most appropriate

paradigm for this study. Pragmatism provides a conceptual and theoretical framework that allowed the freedom to move between constructivist and post-positivist positions in a holistic way, at appropriate and relevant points in the study. Having addressed the purpose and methodology of this study, the next chapter discusses the process, or methods, that were used to conduct the research.

Chapter Four

Methods Chapter

4.1 Introduction

This chapter outlines the methods used for each phase of the study in detail, including how data collected from one phase were analysed before commencement of the next, in a sequential multi-phase approach, as set out in Chapter Three. In the first phase, the sampling and recruitment strategy is discussed, together with the methods that were used to collect and analyse data from young carers in order to identify and develop items to form the first round of the Delphi survey. The second phase discusses the reduction of questionnaire items using a consensus approach between young carers and professionals who work with them. The rationale and process of recruiting participants, and subsequently collecting and analysing data in phase two is discussed, concluding with information regarding a national expert panel, who reviewed the findings and helped finalise the items for inclusion in the CAT-YC. The third and final phase involved evaluating the pilot phase of testing the CAT-YC; information is provided about recruitment, data collection and analysis.

As methods and research ethics are interconnected (Morrow, 2008), ethical considerations throughout the study are discussed, and a flow chart provides a visual representation of the process followed during recruitment for each phase. The chapter concludes with a summary, before the study findings are discussed in detail in the chapters that follow. First, however, some of the benefits and challenges of conducting research with children and young people as participants is considered.

4.2 Benefits and Challenges of Research with Children and Young People

The first objective of this study was to explore the experiences of young carers aged 11-18, and identify factors causing them challenges during their caring experience. As such, it was important to hear their voices and perspectives (McAndrew et al. 2011; Phelps, 2017). Moreover, their contribution to the study as participants, particularly during the first phase, ensured their lived experiences were represented accurately and not just understood from existing literature (Shaw, Brady and Davey, 2011). Their participation during later phases also

gave them the opportunity to identify, or offer a different perspective on, issues that might otherwise have been missed (Worrall, 2000; Kirby, 2004).

However, one of the challenges when including children and young people as participants in research is they may be reluctant to discuss sensitive issues if they are worried their parents, or other authority figures, may find out (Kennan, Fives and Canavan, 2012; McDonagh and Bateman, 2012; Aldridge et al. 2016). Therefore, establishing and maintaining confidentiality, and its limits, with and between participants required careful handling, particularly during the first phase. Gatekeepers, who are the professionals at the organisations controlling access to young people (Cree, Kay and Tisdall, 2002; Tinson, 2009), were essential in this phase, not just for accessing and recruiting participants, but also in helping develop an appropriate working relationship with the young carers (Lewis and Lindsay, 2000; Polit and Beck, 2017). Other challenges related to ensuring participants were able to give informed assent or consent from their parents/legal guardians to take part, and were protected from harm as far as reasonably possible (Masson, 2004; Alderson and Morrow, 2011). This and other ethical considerations are discussed in more detail in section 4.6 later in the chapter.

Although the first objective of this study was to explore the experiences of young carers and identify factors causing them challenges from their caring role, the overall purpose was to develop a short triage tool for use *with* young carers *by* professionals. Therefore, whilst the items in the CAT-YC have been generated from issues raised by young carers, these were balanced with the views of those who will be involved with its administration, signposting and follow up of support or actions. That said, young carers' voices were retained as much as possible, and they were asked to comment on key emerging findings throughout the study, in accordance with National Children's Bureau guidelines (Shaw, Brady and Davey, 2011).

4.3 Phase One

This phase of the project aimed to expand on the findings from the first literature review, which considered the impact of caring on young carers aged 11-18, of a family member with a progressive or long-term illness or disability. It addressed the first objective, which was:

1. *To explore the experiences of young carers aged 11-18, and identify factors causing them challenges during their caring experience*

As such, this required a qualitative approach in order to capture the participants' subjective experiences, in their own words (Frost, 2011; Green and Thorogood, 2014; Bryman, 2016).

4.3.1 Sample for Phase One

Drawing on the technique employed in developing the original CAT (Knighting et al. 2015, 2016), purposive sampling was used to recruit participants aged 11-18, mainly from young carers' centres in North West England. The overall purpose of this type of sampling was to generate an appropriate sample, with a range of ages and genders to address the research aims and objectives (Plano Clark and Cresswell, 2008; Hunt and Lathlean, 2015). Purposive sampling was important, as it targets pre-specified groups, who are sought out for the experiences and knowledge they can provide to a study (Green and Thorogood, 2014; Bryman, 2016). However, this does not necessarily make them representative of the whole population being studied (Hunt and Lathlean, 2015), and this is considered further in the limitations section in chapter nine.

The sample strategy for this phase of the study was to recruit enough participants in order to achieve data saturation. This is the point at which either no new information is obtained from participants (Guest, Bunce and Johnson, 2006; Polit and Beck, 2017), or there is enough information to be able to replicate a study (Walker, 2012; O'Reilly and Parker, 2013). There is much disagreement in the literature as to how many participants are required in a qualitative study to reach data saturation (Mason, 2010; Fusch and Ness, 2015). An initial sample of 20-25 participants was considered to be of sufficient size to address the first objective of the study adequately, with a caveat to increase the sample size following analysis if felt necessary (Hunt and Lathlean, 2015). Table 14 on the following page represents the inclusion and exclusion criteria for young carers considered for the sample:

Table 14: Inclusion and Exclusion Criteria for Young Carer Participants

Inclusion Criteria	Exclusion Criteria
Must be aged 11-18	Any young person not meeting the inclusion criteria
Must be living with and caring for a family member with a progressive or long-term illness or disability	Paid carers
Must have appropriate consent and assent to take part	Children in the care of the Local Authority

The age range of 11-18 was chosen to ensure that the participants would be old enough to understand the questions and purpose of the study (Morris et al. 2015), but young enough to be defined as young carers (Children and Families Act, 2014).

4.3.2 Recruitment for Phase One

Staff members at several young carers' centres were visited, and an additional meeting was held with the regional manager of a large children's charity that supports young carers, to discuss all aspects of the study and establish their support for it. The young carers' centres were visited again when young carers were present and study documentation was created following consultation with, and feedback from them, to ensure content and readability were age appropriate (Alderson, 2007; Lambert and Glacken, 2011). Although written information is vital for participants, Lambert and Glacken (2011) highlight the importance of conversing and engaging with children and young people themselves, to explain the research and check their understanding, before they consider participation. This also gave some of the potential participants the opportunity to meet the researcher and ask questions in a familiar, supportive environment (McDonagh and Bateman, 2012).

As levels of comprehension and sensitivities can vary substantially at different ages (Kennedy, Kools and Krueger, 2001; Gibson, 2007; Stewart and Shamdasani 2014), the participants were separated into two age groups; 11-15 year olds and 16-18 year olds. Information packs containing the documents set out in Figure 7, section 4.6, were then provided to staff for appropriate dissipation to those young carers who staff ascertained met the inclusion criteria.

4.3.3 Focus Groups and Interviews

A focus group, using a semi-structured approach, was chosen as one of the methods for collecting data as it can be a useful means to gain information on the participants' thoughts, feelings and ideas on a particular subject, within a supportive environment (Kennedy, Kools and Krueger, 2001; Krueger and Casey, 2014; Stewart and Shamdasani, 2014). Focus groups can be particularly useful for obtaining data from children and young people, as they may encourage confidence to speak up amongst timid participants (Kennedy et al. 2001; McDonagh and Bateman, 2012). Moreover, some young people find talking to a researcher individually can make them feel vulnerable (Nairn and Clarke, 2012). Focus groups can also help redress the power imbalance that can occur in one-to-one interviews, by encouraging children and young people to feel they are sharing experiences with peers, rather than being questioned by an adult (MacPhail, 2001; Greene and Hogan, 2005). Furthermore, participants can build on each other's responses and come up with thoughts they may not have considered in an individual interview (Richardson, Jinks and Roberts, 2009; McDonagh and Bateman, 2012).

However, there are also potential difficulties associated with focus groups involving children and young people, such as fatigue, or maintaining engagement for the duration of the focus group discussion (Gibson, 2007; Krueger and Casey, 2014; Stewart and Shamdasani, 2014). Moreover, although some participants may find the experience emancipatory; others, who are shy or not confident to speak up, may find it difficult to contribute, or even feel oppressed by the more dominant members of a group (Greene and Hogan, 2005; Colucci, 2007). Participants were therefore reminded that they were not being tested or judged on their caring role, that everything they said was important and welcomed, and they were encouraged to be respectful of each person's views (Goodman and Evans, 2015).

Discussion of ground rules surrounding confidentiality was also made clear at the start of the focus group, in order to try to mitigate against breaches between participants (Greene and Hogan, 2005; Shaw, Brady and Davey, 2011). Although it is not possible to guarantee confidentiality will be maintained between participants when using focus groups, participants

were reminded prior to the start of the group meeting to have regard for each other and not repeat any of the contents of the discussion outside of the group (Smith, 1995; Jones, 2003; Shaw, Brady and Davey, 2011).

There is no standard optimum group size when considering focus groups involving children and young people, although groups of up to eight are suggested to be best for children and young people over ten years of age, as in this study (Horner, 2000; Gibson, 2007; Krueger and Casey, 2014). However, Goodman and Evans (2015) suggest it is advisable to invite more than the required number of participants, to counter inevitable non-attendance, therefore ten young carers were invited to take part in a focus group, and nine of them participated.

As staff at the centres visited had previously indicated that young carers aged 16-18 typically attended in fewer numbers and only sporadically, they were invited to take part in individual semi-structured telephone or face-to-face interviews. Additionally, individual face-to-face interviews were arranged at either a young carers' centre, or at the family home for young carers aged 11-15 who were unable or unwilling to participate in the focus group (Lewis and Lindsay, 2000; Westcott and Littleton, 2005). Altogether, 17 young carers took part in individual interviews.

4.3.4 Data Collection Methods for Phase One

A focus group was arranged for the 11-15 year olds, held at one of the young carers' centres. To try to mitigate against fatigue or non-contribution, the session was planned to last no more than 45 minutes and was structured in a way that allowed time for friendly introductions and clarification about the purpose of the group discussion, and time to debrief at the end (Earley, Cushway and Cassidy, 2007; Goodman and Evans, 2015). A warm up activity was used to encourage participation, whereby participants wrote words that they associated with being a young carer onto a large sheet of paper. Once no new words were forthcoming, participants were encouraged to talk about what they had written (Colucci, 2007). This helped initiate the discussion, which was then guided by a semi-structured schedule of questions (Lewis and Lindsay, 2000; Greene and Hogan, 2005).

The focus group was led by a facilitator and co-facilitator (Bloor et al. 2001; Krueger and Casey, 2014). The facilitator drew on her interpersonal skills gained when working as a counsellor with young people prior to this project and facilitated the discussion, asking questions and ensuring the focus of the topic was maintained (Kitzinger, 1996; Bloor et al. 2001; Goodman and Evans, 2015). The co-facilitator supervised audio equipment, which digitally captured the discussion for later transcription (Dawson, 2009; Bryman, 2016). At the end of the discussion, participants were invited to write any final thoughts they wanted to express, but had not said, onto a postcard and post them into a box. This gave participants the opportunity to comment on any issues they did not want to share with others (Punch, 2005; Colucci, 2007) and provided an appropriate ending to the session. Further details of the data collection process from the focus group are included in the next chapter.

Individual face-to face interviews for young carers aged 11-15 and 16-18 took place at either a young carers' centre or at the family home. An additional option was proffered to young carers aged 16-18 of meeting at Edge Hill University or participating in a telephone interview, however none of the participants chose this option. The interviews followed a semi-structured format of having both pre-determined and open-ended questions, in order to ensure the focus of the interview was maintained, whist retaining the flexibility to follow issues not anticipated (Britten, 2007; Tod, 2015).

Advantages of holding interviews at a young carer's home included comfort and familiarity for the young carer in an environment where they felt safe, together with practical benefits of not having to travel, or leave the family member they care for (Coad et al. 2015). However, a disadvantage when interviewing young people at home is that other family members or friends can enter or stay within the interview space, thereby potentially influencing the young person's responses (Coad et al. 2015). To try to mitigate against being disturbed, time was spent before the interviews started, to negotiate who would be present and where the interviews would be conducted. This was balanced with safeguarding issues; therefore, interviews were not conducted in bedrooms, and a parent or guardian was either present in the room (if requested), or within calling distance if not (Shaw, Brady and Davey, 2011).

4.3.5 Data Analysis for Phase One

At the end of the interviews and focus group discussion, the main points emerging were summarised and relayed to the participants, to check whether they felt it was an accurate reflection of the discussion (Shaw, Brady and Davey, 2011; Stewart and Shamdasani, 2014). Additionally, they were asked if there was anything else they would like to add that had not been discussed (Bloor, 2001; Krueger and Casey, 2014). Reflecting and clarifying on the discussions provided initial central issues to emerge for analysis (Jones, 2003; Goodman and Evans, 2015). After the focus group, the facilitator also debriefed with the co-facilitator, to discuss issues that may have affected analysis, such as areas of agreement or disagreement, or how views may have been modified or reinforced during the group discussion (Jones, 2003; Stewart and Shamdasani, 2014; Goodman and Evans, 2015).

Data were transcribed verbatim from the audio-recordings as soon as possible after it was recorded, and a thematic analysis approach was used to analyse it, using the first five of the six steps suggested for this approach by Braun and Clarke (2006; 2013), as shown in Table 15 below.

Table 15: Steps in Thematic Analysis, adapted from Braun and Clarke (2006)

Steps	Stages	Description of Process
1	Familiarisation	Transcribing, reading, noting initial ideas
2	Generating Initial Codes	Coding and collating interesting and relevant data
3	Searching for Themes	Collating codes into themes
4	Reviewing Themes	Checking if themes work across data set
5	Defining and Naming Themes	Refining the specifics of each theme
6	Producing Report	Producing a scholarly report of analysis

Step one involved becoming fully immersed in the data by reading and re-reading the transcripts to become familiar with the entire content and context of them (Braun and Clarke, 2006, 2013; Polit and Beck, 2017). Initial ideas were noted down on the transcripts, ready for

the first level of coding in step two. The process of coding involved organising data into meaningful codes (Miles, Huberman and Saldana, 2014; Hunt and Lathlean, 2015). In step three, the focus of the analysis shifted from the individual codes to the broader level of overarching themes, and some of the codes were reduced by either combining them or eliminating them (Braun and Clarke, 2006, 2013; Polit and Beck, 2017). The themes were reviewed and refined on two levels during step four. The first level required checking the coded data within each theme to ensure it formed a coherent pattern within the theme. The second level required checking the themes against the entire data set to make sure they 'worked' and to code any additional data within themes that may have been missed (Braun and Clarke, 2006, 2013). Finally, in step five, the themes were defined, and a detailed analysis was conducted for each individual theme, together with consideration given to the relationship of the themes with each other (Braun and Clarke, 2006, 2013; Hunt and Lathlean, 2015).

To enhance credibility of the findings, a sample of data was analysed by the supervisory team, and the final themes discussed with them to establish agreement with the findings (Dawson, 2009; O'Brien and Jack, 2009; Noble and Smith, 2015; Bryman, 2016). The findings from this phase were then used, along with key factors identified in existing literature, to develop items for a questionnaire (Keeney, 2015). The resultant questionnaire was used to form and replace the first round of the modified Delphi Survey, which will be discussed further in phase two.

4.4 Phase Two

This phase of the project aimed to address the second objective of the study:

2. *To seek the views and consensus from young carers and professionals on the items to be included in the CAT-YC*

To meet this objective, two methods were used to collect qualitative and quantitative data from the survey questionnaire developed from the findings in phase one. A modified online Delphi survey was used with young carers aged 16-18 and professionals who work with young carers; a nominal group technique (NGT) was used to collect survey data from young carers aged 11-15, who attended a series of consensus small group events. This was to ensure all parties had equal opportunities to participate, and the rationale for using two approaches is

elaborated on further in the next section.

4.4.1 Development of Questionnaire Items for the Delphi Survey and NGT

Separate methods were chosen to collect and collate this data, as although online surveys are an efficient method of collecting data from a wide range of participants, web-based surveys are often not recommended for younger children (Greene and Hogan, 2005). Furthermore, it is recognised that it can be difficult to encourage younger children to take part in Delphi style research surveys (Morris et al. 2015).

4.4.2 Delphi Surveys

For those aged 16 and above, Delphi surveys have been used extensively in healthcare research (Keeney, Hasson and McKenna, 2011; Keeney, 2015) and a Delphi survey was successfully used with adult carers and professionals during the development of the original CAT (Knighting et al. 2015, 2016). A Delphi survey is a structured process that uses a series of questionnaires or rounds to gather information and is continued until group consensus is reached, or sufficient information has been obtained (Hasson, Keeney and McKenna, 2000; MacPhail, 2001; Keeney, Hasson and McKenna, 2011). The main premise of this approach is based on the assumption that group opinion is more valid than individual opinion and therefore the aim is to gain consensus on a particular issue or set of issues (Creswell and Plano Clark, 2011; Keeney, 2015).

There is no standard agreement in the literature about the definition of this approach; it has been referred to as Delphi, Delphi survey, Delphi technique and Delphi method (Mullen, 2003). Similarly, various modified versions have evolved, including the modified Delphi (McKenna, 1994b), the policy Delphi (Crisp et al. 1997), the real-time Delphi (Beretta, 1996) and the e-Delphi (Sheik et al. 2008). For the purposes of this study, a modified version of the Delphi survey was used, with the first round using items developed from qualitative data gained from the focus group and interviews (Keeney, Hasson and McKenna, 2011; Keeney, 2015) and from existing literature, as in the development of the CAT (Knighting et al. 2015, 2016).

4.4.3 Sample and Recruitment for the Delphi Survey

Delphi survey panels can vary considerably in size and composition of members, depending on the purpose of the project (Cantrill, Sibbald and Buetow, 1996; Hsu and Sanford, 2007). In healthcare, most published Delphi survey studies report sample sizes of between 10 and 100 participants (Akins, Tolson and Cole, 2005). Although Delphi survey panels are often referred to as comprising of 'experts', with the implicit assumption of professional qualifications or high status, Cantrill, Sibbald and Buetow (1996:69) argue that in the field of health care '*the definition of [an expert] should include any individual with relevant knowledge and experience of a particular topic, including patients and carers.*' Similarly, Keeney, Hasson and McKenna, (2011) note the importance of selecting the most appropriate participants to be part of a Delphi panel, therefore a purposive sampling approach was used to recruit young carers aged 16-18 (including, but not limited to, those who participated in phase one) and professionals working with young carers (Green and Thorogood, 2014; Bryman, 2016). Emails were used to distribute information about the study, with invitations to take part in the Delphi survey. These were sent out to national young carers' organisations and charities known to support young carers for inclusion in newsletters. Staff at those organisations were asked to cascade information to other relevant professionals and young carers aged 16-18, as appropriate (McLeod, 2003; Hunt and Lathlean, 2015). Furthermore, the social media site Twitter was used to advertise the study.

4.4.4 Data Collection for the Delphi Survey

The Delphi survey was created and posted online using Survey-Monkey® (www.surveymonkey.com). The first part of the Delphi survey collected anonymous demographic information about the participants, such as professional role (if any) and geographical location (Keeney, Hasson and McKenna, 2011; Knighting et al. 2015, 2016). In addition, young carers aged 16-18 were asked their age, how long they had been carers for, and their family member's medical condition, if known. The second part listed comments based on the themes identified in phase one, and participants were asked to rate these comments, or items, on a Likert scale from (1) '*not at all important*' to (5) '*extremely important*' (Knighting et al. 2015, 2016). A comment box was provided next to each topic to allow participants to express any issues, or to highlight any items they felt were missing from

the CAT-YC. In the third part, the participants were asked to rank the topics in order of priority to start reaching a consensus of items to include in the CAT-YC (Knighting et al. 2015, 2016). They were also asked their views on who should use the CAT-YC with young carers, and how often potential needs should be reviewed. A final section contained useful contacts of national organisations that provide emotional support to young people, such as ChildLine and Kooth, in case of distress occurring when completing the survey (Nairn and Clarke, 2012; Knighting et al. 2015, 2016).

There are no strict guidelines as to how many rounds a Delphi survey should contain, as it depends on the time available and purpose for gaining consensus, (Keeney, Hasson and McKenna, 2011; Keeney, 2015). The classical original Delphi used four rounds (Young and Hogben, 1978), but one drawback of using four or more rounds is that panel members can lose interest or drop out (Black, 2006; Keeney, 2015). However, as this study used a modified version of the Delphi survey, three rounds were deemed to be sufficient to reach consensus (Beech, 1997; Keeney, 2015; Knighting et al. 2015, 2016). Each participant received anonymous feedback on the items reaching consensus by the group, before proceeding to the next round (Keeney, Hasson and McKenna, 2011; Keeney, 2015). Ensuring the feedback was anonymous is particularly important with young people, as they often defer to adults, and could be implicitly influenced by their responses (McDonagh and Bateman, 2012).

For those organisations who agreed to support dissemination of the Delphi survey, reminders were sent out by email to participants who had not responded a week after it commenced, as this has been found to enhance the response rate (McKenna and Keeney, 2004; Keeney, Hasson and McKenna, 2011). The Delphi survey only remained open for six weeks between rounds, to try to combat against participants losing interest (Keeney, Hasson and McKenna, 2011; Keeney, 2015).

4.4.5 Nominal Group Technique Consensus Groups for 11-15 Year Olds

Meeting younger carers aged 11-15 face-to-face was an alternative way to gather data during this phase, for the reasons suggested above by Greene and Hogan (2005) and Morris et al. (2015). Additionally, McDonagh and Bateman (2012) highlight that parents could influence

young people's completion of surveys when carried out by post or online, and therefore arranging to complete them away from home may have helped mitigate against this. Methods such as nominal group technique (NGT), focus groups and thought mapping groups have all been used with young school-aged people to gather information and views (MacPhail, 2001; Milnes et al. 2013). Focus groups or thought mapping groups were considered inappropriate as the purpose of holding the consensus group meetings was to gather survey data from young carers, in a similar format to that used in the Delphi rounds, rather than through discussion.

NGT approaches also differ from focus groups and thought mapping groups, in that participants can work in the presence of each other, but write their answers down independently (MacPhail, 2001; Black, 2006). This may prevent the dominance of more vocal members influencing other participants, as can happen in conventional focus groups (Denscombe, 2014; Krueger and Casey, 2014; Goodman and Evans, 2015). Typically, NGT approaches are unstructured, however, evidence suggests that modifying NGT approaches by having a more structured format is particularly effective for gathering data from young people (MacPhail, 2001; Milnes et al. 2013). Therefore, for the purposes of this study, the NGT approach was modified, as reported in section 4.4.7 on the next page. Using such an approach, in tandem with the Delphi process, ensured that all young carers who wished to participate in the study had the opportunity to complete the survey and provide information and feedback in a supportive environment (Bailey et al. 2015).

4.4.6 Sample and Recruitment for the NGT Consensus Groups

Social media was not used to recruit young carers aged 11-15, due to guidelines recommending that young people under 14 should not have social media accounts (Schurgin and Clarke-Pearson, 2011; UK Council for Child Internet Safety, 2016). Therefore, a purposive sampling approach was used to recruit young carers aged 11-15 to take part in the NGT consensus group meetings, via young carers' support groups and a national charity supporting young carers (Bryman, 2016; Green and Thorogood, 2014). Between eight and ten participants are recommended for consensus groups (Polit and Beck, 2017), therefore the same strategy of oversampling used in phase one for the focus group, was employed in this

phase, to try and achieve three groups of six to eight participants each (Goodman and Evans, 2015).

Participants aged 11-15 who took part in the focus group and interviews in phase one were invited to take part in the NGT consensus group meetings. One of the advantages of young carers having taken part in phase one, was they may have felt more committed to the study, and willing to participate in further phases (McKenna, 1994b; Morris et al. 2015). However, due to the anecdotally acknowledged high attrition rates of members attending young carers' support groups, additional young carers meeting the inclusion criteria and able to provide appropriate consent and assent were also invited to take part in these meetings.

4.4.7 Data Collection for the NGT Consensus Groups

Consensus group meetings were held in parallel with the timing of the Delphi survey rounds, at the venues identified in phase one. The wording of the questionnaire used in the online Delphi survey was modified slightly for 11-15 year olds and piloted with several young people before the groups met for the first time, to ensure the wording was appropriate and understandable (Lambert and Glacken, 2011; McDonagh and Bateman, 2012). The NGT consensus meetings took approximately 60 minutes each to facilitate, including the warm up activity and consent process, and an additional researcher was present to help collect data.

The modified survey was given to each participant as part of a pack of laminated coloured cards, with each card representing a topic and containing the items within that topic. Instructions were given to the group to rate each item by themselves, and then rank the topics in order of importance, as in the Delphi survey process above (Knighting et al. 2015, 2016). Consideration was given to using a different type of rating system to a Likert scale, such as a visual analogue scale, however research by Laerhoven, van der Zaag and Derkx (2004) comparing scales used by children aged 6-18, concluded that young people of all ages preferred Likert scales. After the participants had all completed the survey, any additional comments made by them were noted down, following a brief discussion (Milnes et al. 2013).

The groups then met again, timed to synchronise with the next Delphi survey data collection round, and the same process was followed as in the first consensus group meetings. The participants were asked to individually rate the items on the survey using a Likert scale from (1) '*not at all important'* to (5) '*extremely important'* (Knighting et al. 2015, 2016), in order to try to reach consensus on the items to include in the CAT-YC. Again, after the surveys were collected in, the participants were debriefed and given the opportunity to talk about how they had found the process.

4.4.8 Data Analysis for Phase Two

The same methods of analysis were used for both the online Delphi surveys and NGT consensus group surveys. Qualitative data were analysed thematically, as in phase one (Braun and Clarke, 2006, 2013; Miles, Huberman and Saldana, 2014; Polit and Beck, 2017). Quantitative data were entered into the IBM SPSS Statistics, Version 25, for analysis (Armonk, NY; IBM Corp, 2018). Descriptive statistics, relating to profession (for professionals), or age, gender and length of time as a carer (for young carers), were used to describe the samples according to the demographic information gained from the first part of the surveys (Field, 2013; Bryman, 2016). Data from the second and third parts of the surveys were analysed using measures of central tendency, frequency and levels of dispersion (Interquartile Range [IQR]) to provide information concerning the collective judgements of the respondents (Oppenheim, 2000; Munro, 2005; Field, 2013).

There is no clearly defined acceptable level of consensus for Delphi studies (Keeney, Hasson and McKenna (2011). Some studies have used 51% as an acceptable threshold (e.g. Loughlin and Moore, 1979; McKenna, 1994a; De Lima et al. 2007). Some have used 66% (e.g. Boyce et al. 1993) or even 80% (e.g. Ulschak, 1983). In the development of the original CAT, the level of consensus to include an item was set at 70% of participants rating the item as equal to or greater than a mean level of (4) (*very important*), which was subsequently revised to a median level of (5) (*extremely important*)*,* out of a five point Likert scale due to the high level of rating and consensus across the items by both carers and professionals (Knighting et al. 2015, 2016). In the development of the CAT-YC, the initial consensus level was similarly set to 70% of participants rating an item as equal to or greater than a median level of (4) (*very important*).

However, this level was lowered to 60% as it became apparent on initial analysis that there were very diffuse levels of consensus in the young carer cohort. A median level of (4) (*very important*) was still used to establish 60% consensus, as research by Laerhoven, van der Zaag and Derkx (2004) reports that young people often display end-aversion bias when answering Likert scale questionnaires, therefore (5) (*extremely important*) was deemed too high.

The following pre-determined consensus criteria were therefore used:

Criterion to accept an item: at least 60% of the young carer and professional panels rated an item as (4) (*very important*) or (5) (*extremely important*). In Round 2, accepted items were removed from the survey as they did not require any further rating, before proceeding to the next round.

Criterion for re-rating an item: if 60% of one panel rated an item as (4) (*very important*) or (5) (*extremely important*) but the other panel did not, suggesting disagreement between panels, they were retained for re-rating in Round 3 (McKenna, Hasson and Keeney, 2015).

Criterion for rejecting an item: any items that did not meet the 60% criteria in either panel or the total sample were removed from the survey.

In Round 3, controlled feedback was given for the remaining items using the group median score to show participants the level and range each item was rated at previously (Keeney, Hasson and McKenna, 2011; Keeney, 2015). Once overall levels of consensus were agreed on for the items, the mean and standard deviation (SD) were calculated for each item in order from '*most important*' to '*least important*' (McKenna, Hasson and Keeney, 2015). The highest ranking items were then sent to an expert panel, so they could further reduce the items for the CAT-YC. The expert panel process is outlined below.

4.4.9 National Expert Panel Review

Drawing upon the development of the initial CAT (Knighting et al. 2015, 2016), findings from Rounds 2 and 3 were summarised, reviewed and priority ranked by an expert panel consisting of young carers aged 16-18, and professionals with a national profile from leading national organisations that support and campaign for young carers. This was not a commenting

exercise, but a necessary step in reaching consensus and finalising the items for inclusion in the CAT-YC (Knighting et al. 2015, 2016). Members of the expert panel were approached and contacted either by gatekeepers or by email, with a link to an online survey created from the top ranked items in the Delphi survey, and invited to individually comment on, select and rank ten items from the findings.

4.5 Phase Three

This phase of the study aimed to address the third and fourth objectives, which were:

3. *To consult with young carers and professionals on the pilot version of the CAT-YC to finalise format, instructions and wording*

4. *To explore the experiences of young carers and professionals when using the CAT-YC*

4.5.1 Development of the Pilot CAT-YC

The pilot CAT-YC contained ten items of carer challenges that were ranked highest in phase two, together with a three-point traffic light scoring system to identify low, moderate and high levels of need, based on the original CAT (Knighting et al. 2015, 2016). It also contained a 'suggested next steps' section, with guidance for professionals on the appropriate action to be taken for any items that received a moderate or high need score when administering the CAT-YC. This guidance, however, was not intended to replace the individual staff member's professional responsibility for taking action, which would be in accordance with their organisation's policies and procedures.

4.5.2 Consultations on the Pilot CAT-YC

Before using the CAT-YC in a pilot study, views and comments were sought on its wording, comprehension and layout by several young carers (n=2) and professionals (n=4) who were involved in earlier phases of the study (Alderson, 2007; Lambert and Glacken, 2011). This was to ensure the content was clear to understand by the parties most likely to use it, and provided the opportunity for minor changes to be made to ensure it was fit-for-purpose. Additionally, a user guide for staff guidance sheet was developed and prepared for professionals, containing instructions on how to use the CAT-YC.

4.5.3 Pilot and Evaluation of the CAT-YC

The carers' centres involved in earlier phases of the study piloted the draft version of the CAT-YC for usability by their organisations. The organisational pilot phase was evaluated for this study to highlight any potential issues that were not foreseen in the developmental stage. This provided the opportunity to address them before the CAT-YC is launched on a larger scale (Burns and Grove, 2010; McKenna, Hasson and Keeney, 2015; Knighting et al. 2015, 2016).

4.5.4 Pilot Evaluation Sample and Recruitment

The initial pilot phase of the original CAT study involved eight healthcare professionals and seven family carers, who then provided feedback via forms and telephone interviews, respectively (Knighting et al. 2015, 2016). The pilot stage for this study was undertaken by the carers' centres themselves, and then evaluated by involving ten participants, comprising of four young carers from within the two age ranges: 11-15 year olds and 16-18 year olds; and six professionals working with young carers. All participants were recruited purposively from the young carers' centres used in the earlier phases of the study (Green and Thorogood, 2014; Bryman, 2016).

4.5.5 Pilot Evaluation Data Collection

Information detailing how the CAT-YC should be administered was provided to professionals at the young carers' centres, who then completed it with individual young carers in accordance with their centres' own organisational procedures. Professionals who were part of the pilot study were given relevant study documentation and invited to take part in an interview about their experiences of administering the CAT-YC. The interviews were semi-structured and questions focused on the time taken to administer the CAT-YC, ease of use, signposting information, and whether the staff members felt the CAT-YC adequately covered all the important issues required in a short triage tool for use with young carers.

Invitations to participate in the evaluation study, along with the relevant participant information sheets and consent/assent forms were given to young carers who staff had completed the CAT-YC with, to take home and consider. Young carers (with their parent/legal guardian's consent if under 16) who responded to the invitation to participate in this phase

of the study, were invited to undertake a short individual interview about their experiences of having the CAT-YC administered, at the young carers' centre they attended. Interview appointments were arranged 2-3 weeks after administration of the CAT-YC, to allow time for the young carers to have any resulting assessments, actions, or signposting to appropriate support. However, staff at the young carers' centre were contacted first, to check whether they were aware of any change of circumstances that may have affected the young person from participating, such as the hospitalisation or death of the family member they care for.

Although the pilot stage of the original CAT study used telephone interviews with carers (Knighting et al. 2015, 2016), for this study face-to-face interviews were conducted with young carers, as the participants were from the same geographical area. Additionally, face-to-face interviews are preferred to telephone interviews by almost twice as many young people, and often produce more useful data (Vogl, 2013). This also made it easier to appraise the situation with regard to stopping the interview if the participant became distressed (Tod, 2015). Interviews with both professionals and young carers were digitally recorded and transcribed before analysis (Dawson, 2009; Bryman, 2016).

4.5.6 Pilot Evaluation Data Analysis

Data collected from the interviews were subject to content analysis (Hsieh and Shannon, 2005; Vaismoradi, Turunen and Bondas, 2013). To enhance credibility of the findings, a sample of data were analysed by the supervisory team, to establish if they concurred with the findings (Dawson, 2009; O'Brien and Jack, 2009; Bryman, 2016). Drawing on the procedures followed during the development of the CAT (Knighting et al. 2015, 2016), any adjustments to the final version of the CAT-YC were made in accordance with the findings from the analysis of data in the pilot evaluation phase.

4.6 Ethical Considerations

Ethical guidance was paramount throughout the study period and this was obtained from guidelines set out in the Edge Hill University Ethical Guidance for Undertaking Research with Children and Young People (Edge Hill University, 2012); the University Code of Practice for the Conduct of Research (Edge Hill University, 2014) and the University Policy for Research

Ethics (Edge Hill University, 2017). Before any formal data collection began, ethical approval was sought for each phase of the study from the Faculty of Health and Social Care Research and Ethics Committee (FREC) within Edge Hill University. Ethical approval was also sought and obtained from Barnardo's Research Ethics Committee (BREC) for the second and third phases of the study. Copies of all the relevant ethical approval letters are contained in Appendices 2 and 3.

Study documentation for each phase of the study is represented in Figure 7 on the following page. Due to the amount of documentation prepared, two documents from each phase are included in Appendices 4-9 as exemplars of the study documents.

Phase One	• Invitation and information for young carers aged 11-15 (focus group/interviews) • Information sheet for parents/legal guardians of 11-15s for this phase • Consent form for parents/legal guardians of 11-15s for this phase • Assent form for 11-15s for this phase • Invitation & information for young carers aged 16-18s (interviews) • Consent form for 16-18s for this phase • Information sheet listing support organisations for young carers (all phases) (Additional study documents: semi-structured interview schedules for interviews & focus group – 2 documents)
Phase Two	• Invitation for young carers aged 11-15 to take part in consensus groups • Information sheet for parents/legal guardians of 11-15s for this phase • Consent form for parents/legal guardians of 11-15s for this phase • Assent form for 11-15s for this phase • Flyer advertising study to 16-18s to take part in Delphi survey • Information sheet for 16-18s to take part in Delphi survey • Information for professionals to take part in Delphi survey • Email & participant information for professionals to take part in expert panel (x2) • Information for 16-18s to take part in expert panel • Sample preface to online Delphi surveys
Phase Three	• Invitation and information for young carers aged 11-15 (pilot study) • Information sheet for parents/legal guardians of 11-15s for this phase • Consent form for parents/legal guardians of 11-15s for this phase • Assent form for 11-15s for this phase • Invitation & information for young carers aged 16-18s for this phase • Consent form for 16-18s for this phase • Sample email to professionals for this phase • Information for professionals to take part in this phase • Consent form for professionals for this phase (Additional study documents: semi-structured interview schedules for interviews with professionals and young carers – 2 documents)

Figure 7: Study Documentation

Ethical issues related to risks and benefits of participation, confidentiality, and the option to withdraw were incorporated into each document, along with the research team's contact details, so that potential participants could request further information if required (Dawson, 2009; Gallagher, 2009). The documents were produced in an age appropriate way, after consultation with young people, to ensure that the younger participants could understand the aims and objectives of the research and what would be required of them (Lambert and Glacken, 2011).

Young carers' well-being was paramount throughout the study and it was important that appropriate consent and assent was obtained during each phase, to protect their dignity, privacy and confidentiality (Nairn and Clarke, 2012). Current guidelines by the British Medical Association (BMA) indicate that at the age of 16, there is a presumption of competence to give valid consent, therefore this was obtained from young carers aged 16-18 (BMA, 2016). Consent from parents/legal guardians was obtained for young carers aged 11-15 and additionally, assent to participate was obtained from the young carers aged 11-15 themselves (McDonagh and Bateman, 2012).

Confidentiality was assured, as far as possible, although it was made clear that if it was felt that there was reasonable cause for concern that a child or young person was suffering harm, this would be reported to a member of staff at the young carer's centre after discussion with the young carer, and appropriate action would be taken in accordance with the organisation's policies and procedures (Morrow, 2008; Alderson and Morrow, 2011). For some young carers, talking about their caring role, and their own and/or their family member's well-being could have been upsetting during any of the phases (Nairn and Clarke, 2012). Therefore, contact details of support organisations such as ChildLine and Kooth were provided for all young carers, in case of distress during or following their participation (Nairn and Clarke, 2012).

Participants were also advised that they could withdraw from the study at any time, without giving a reason (Dawson, 2009; Gallagher, 2009; McDonagh and Bateman, 2012). However, in the first phase, they were advised that whilst data collected during individual interviews could be withdrawn up to seven days from the point of interview, data collected from the

focus group could not be withdrawn, as it would not be possible to identify individual participants' data.

4.6.1 Data Management

The participant information sheets and consent forms, referred to in Figure 7 earlier, contained information about how data would be collected and stored during and after the study (Kirby, 2004; Involve, 2012; Johnson and Long, 2015; General Data Protection Regulation, 2018). Digital audio-recordings from the focus group and interviews were stored using encrypted software, in accordance with Edge Hill University's Data Management guidelines, which recommend data are saved for ten years. The transcribed recordings and all other raw data were anonymised through the use of pseudonyms and scanned onto the university server (Data Protection Act, 2018; Moule and Hek, 2011). Consent forms were stored separately from other data containing personal information in a locked filing cabinet in the researcher's office before being scanned onto the password protected university server, as above (Research Councils UK (RCUK), 2015).

4.6.2 Lone Working Policy

The focus group during phase one and consensus group meetings in phase two were not attended alone as an additional researcher was present, however interviews were, and therefore precautions were taken to ensure personal safety, in accordance with Edge Hill University's Safe Fieldwork Protocol and Health and Safety policy. Furthermore, additional measures were in place to contact the supervision team if any interviews proved to be emotionally challenging, to debrief and facilitate reflection (Tod, 2015).

4.7 Summary

This chapter started by discussing the benefits and challenges of conducting research involving children and young people. The methods used during each of the three phases were then considered in detail, and ethical considerations were discussed. In the following chapters, the results and findings from analysis of each of the phases are considered, and details of the development of the CAT-YC are given.

Chapter Five

Findings from Phase One

5.1 Introduction

This chapter contains a detailed explanation of the findings from phase one of the study and how they were used, along with existing literature, to develop and form items to replace the first round of the Delphi survey in phase two. This level of detail is important, as published guidance on conducting and reporting Delphi studies reiterates the importance of clarity and transparency throughout the process, particularly when using a modified Delphi method (Hasson and Keeney, 2011; Jünger et al. 2017).

The chapter starts by briefly recounting the data collection process and provides demographic details of the participants who took part in the interviews and focus group. It then provides an explanation of how themes and sub-themes were identified and developed from the findings, and supplemented where appropriate by data from existing literature, to form items for the second round of the Delphi survey. The chapter ends with information about how the Delphi survey items were reviewed and refined to increase rigour before phase two commenced.

5.2 Participant Demographics

Data were collected from 26 participants aged 11-18 in five regions of North West England between October 2017 and January 2018. Most of the participants were recruited from dedicated young carers' centres, and several were recruited through a sibling support group that provides respite and activities for siblings of children with life-limiting medical conditions. Additionally, three participants were recruited through the university Faculty of Health and Social Care Service Users and Carers Group. The average age of the participants was 14.7 years, with 15 of the participants reporting their gender as female and 11 as male. In total, 12 participants lived in a household with two parents or legal guardians, and 14 lived in a lone parent household. Fifteen of the care recipients were either one or more of the young carer's parents, eight care recipients were a sibling, and three were a combination of both. Table 16 on the following page provides anonymised participant demographics.

Table 16: Phase One Participants

Interview or Focus Group	Pseudonym	Sex	Age	Family member who receives care	Lone or Dual parent house hold	No. of years as a carer	Medical condition/disability
I	Jenny	F	15	Mother	Lone	3	Multiple sclerosis
I	Noah	M	17	Mother	Lone	5	Brain injury
I	Callum	M	16	Mother	Dual	4	Registered blind
I	Sophie	F	13	Younger sister	Dual	10	Multiple complex medical needs
I	Karl	M	17	Older brother	Lone	4	Cardiac condition related to Down Syndrome
I	Liam	M	14	Younger sister & Mother	Dual	5 2	Rett Syndrome Cancer
I	Joe	M	16	Mother	Lone	3	Fibromyalgia
I	Bianca	F	17	Younger brother	Lone	3	Autistic Spectrum Condition (ASC), ADHD, Dyspraxia
I	Gemma	F	17	Mother	Lone	3	Fibromyalgia
I	Rachael	F	18	Mother	Lone	7	Degenerative spinal condition
I	Daryl	M	11	Older brother	Dual	4	Multiple complex medical issues
I	Cory	M	11	Younger brother	Dual	3	ASC
I	Emma	F	12	Younger brother	Dual	3	ASC
I	Jack	M	16	Mother	Lone	6	Paraplegia
I	Poppy	F	16	Mother	Dual	14	Fibromyalgia
I	Laura	F	18	Mother & Younger brother	Lone	8	Granulomatosis Hearing loss & asthma
I	Ellie	F	17	Younger brother	Dual	11	ASC
FG	Hayley	F	12	Mother	Lone	1	Chronic Obstructive Pulmonary Disease & Myalgic Encephalitis
FG	Kate	F	14	Mother	Dual	14*	Mobility issues; multiple medical issues
FG	Casper	M	13	Mother & Father	Dual	13*	Cerebral Palsy Brain damage
FG	Harry	M	13	Mother	Lone	7	Fibromyalgia & chronic back pain
FG	Tia	F	13	Mother & Older brother	Lone	4	Diabetes & mobility issues ASC
FG	Chantelle	F	13	Mother	Lone	5	Spina Bifida Occulta
FG	Anna	F	14	Younger brother	Dual	7	ASC
FG	Jed	M	14	Mother	Lone	5	Cancer
FG	Daisy	F	12	Mother & Father	Dual	7	Awaiting heart transplant Brain damage/stroke

*** These participants stated they had been young carers '*their whole life*'.**

5.2.1 Individual Interviews

Seventeen individual interviews were conducted, and these took between 13 and 40 minutes to complete, with the average time being 19 minutes. The interviews took place at either a young carers' centre or support group, or for those who were not members of a young carers' centre or support group, at the family home. Data collected from these interviews provided a balance to data collected via participants at dedicated young carers' groups, as different perspectives and experiences were given, thereby reducing any potential for bias from purposive sampling at those sites (Bryman, 2016; Polit and Beck, 2017).

5.2.2 Focus Group

Additionally, a focus group comprising of nine participants aged from 12 to 14 was held at one of the venues and this took 45 minutes to conduct. Not all of the participants had met each other prior to the session, therefore after initial introductions were made and assent obtained, a range of creative methods were used to stimulate conversation between participants and support data collection. Figures 8, 9 and 10 below and overleaf display some of the data collected.

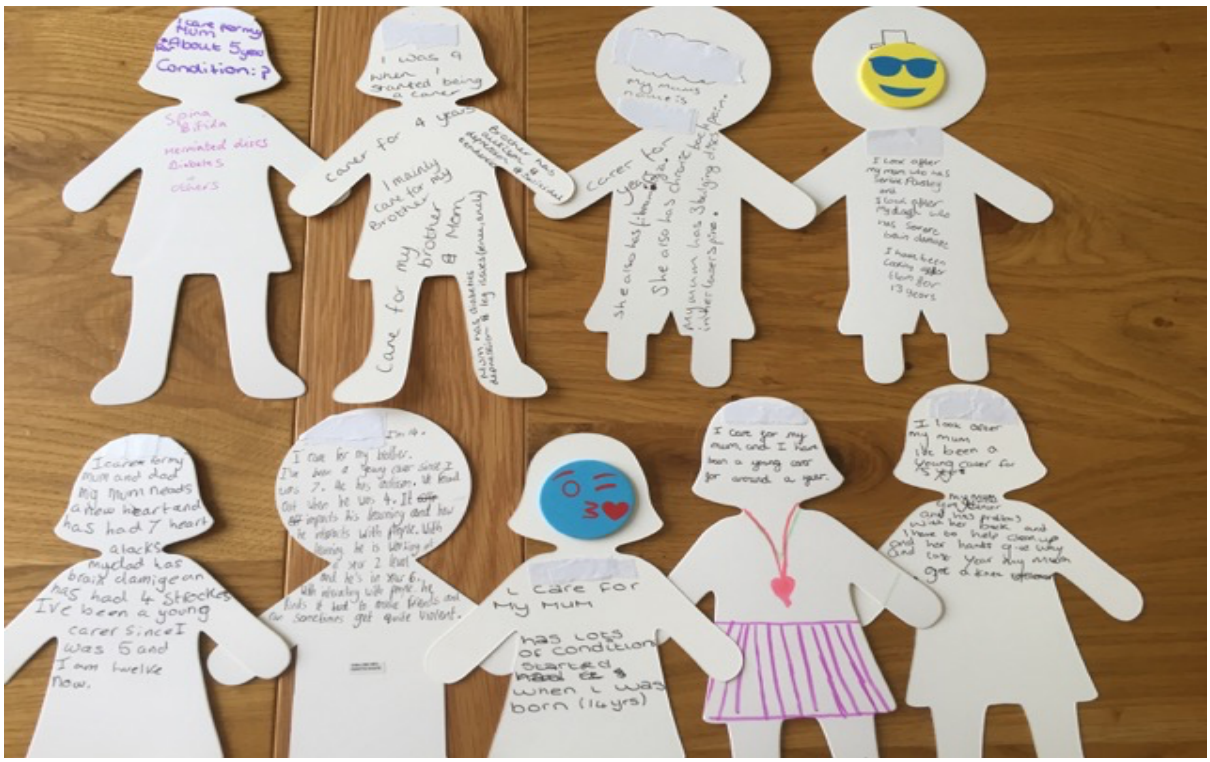


Figure 8: Who do you look after?

Figure 9: Who is a young carer and what do they do?

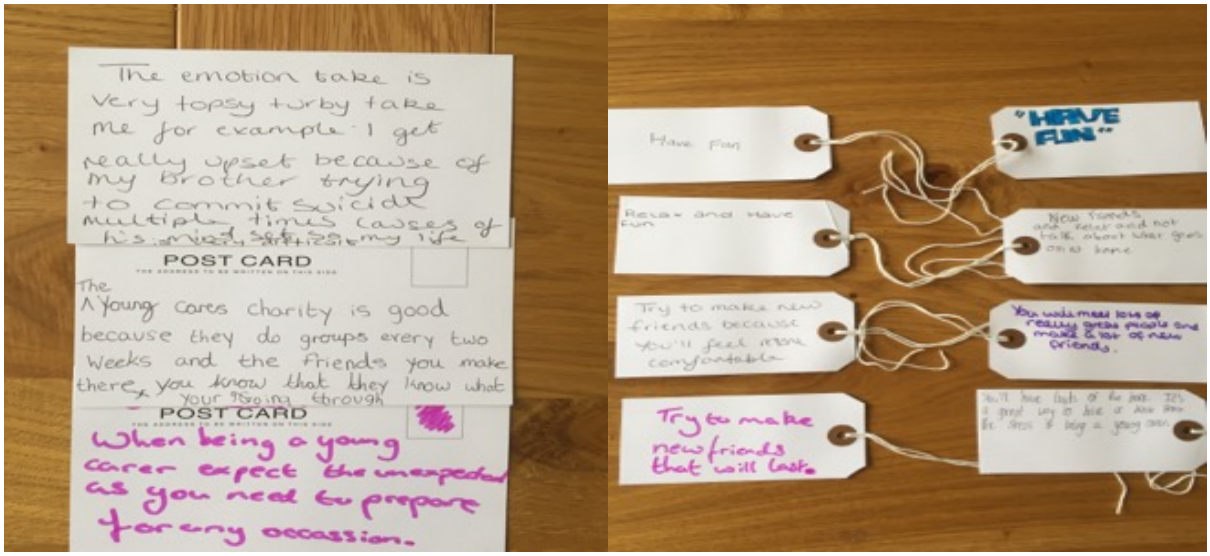


Figure 10: How does caring affect you? Final thoughts?

5.3 A Cautionary Note

It is important to note at this stage that although some of the participants in both the interviews and focus group alluded to the benefits and positive outcomes they experienced as a result of caring, these factors have not been explored in detail in this chapter. This is because the purpose of this phase of the study was to identify items that would help to identify and triage any needs arising from the impact of caring. Therefore, whilst positive outcomes are important to acknowledge conceptually, they were not pursued as they were not relevant for the aim of the phase and ultimately the aim of developing the CAT-YC tool.

The next section describes how the themes and sub-themes identified in the data were developed, as explicitly describing the full analysis process is essential to enhance the credibility of the findings (Noble and Smith, 2015; Bryman, 2016; Polit and Beck, 2017).

5.4 Overarching Themes

It was apparent on analysis that there were two overarching themes in the data: the young carers' situation and caring role within the family home; and their own health and wellbeing. Interestingly, these two themes were also reported in the development of the original CAT for adult carers (Knighting et al. 2015, 2016). Further development of the themes initially identified eight sub-themes. At this point, it became evident that whilst the two overarching themes remained the same, some of the eight sub-themes did not have enough data to support them. They were therefore reviewed and refined again, and some were collapsed into each other, making a total of five remaining sub-themes, as illustrated in Figure 11.

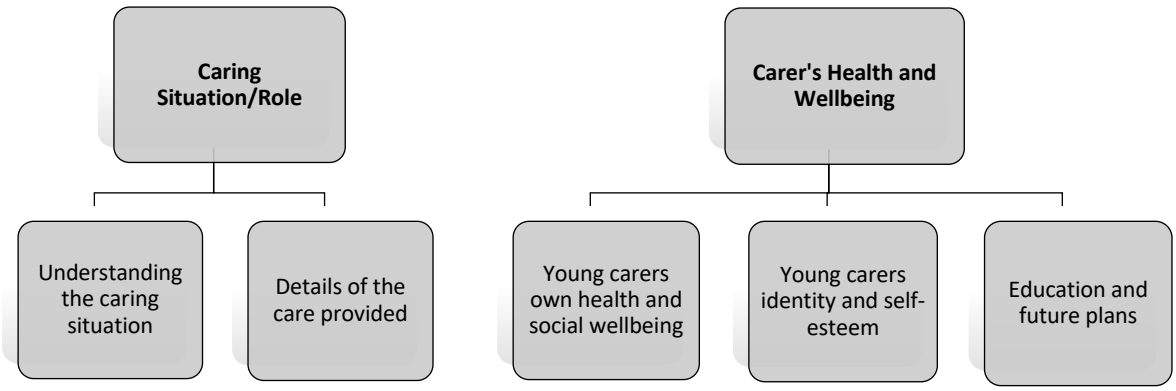


Figure 11: Themes and Sub-themes

5.5 Theme One: Caring Situation/Role

This theme relates to the caring situation at home and what the caring role entails, to help understand any support needs the young carer may have due to providing care. Two clear sub-themes were identified within this theme and each of these are discussed in turn, using anonymised verbatim extracts from the participants to support the analysis.

5.5.1 Sub-theme 1: Understanding the Caring Situation

One of the first considerations when seeking to understand the caring situation was to explore why care was needed, how much time was spent caring, and whether the young

carer's family member was likely to need care for a substantial period of time. Participants reported the length of time they had been caring for ranged between 1 and 14 years, with a median average of five years. Therefore, it was likely that their caring role had impacted their lives over a prolonged period of time. It was difficult to establish how much time most of the participants typically spent in their caring role, with many of them unable to estimate a time period, e.g. Joe (16), who: '*couldn't put a number on it';* Liam (14) who said: *'it depends';* and Daryl (11) who reported that it was *'quite a lot'* . Those that could estimate an amount of time, ranged from '*about an hour each day'* (Callum, 16), to '*three-quarters of my day'* (Jenny, 15). However, two of the participants' responses illustrated the often unpredictable and fluctuating nature of the time spent caring:

> *'It varies really. She has good days and then she has her bad days - it's the time of year. It can depend, because as it gets colder she'll get a cold and things, and usually go into hospital in the winter if she's not well'* (Sophie, 13)

> *'It differs. Because if she's downstairs, then you know she's having a good day - well, as good as she's going to get. If she's downstairs, it means I don't have to necessarily walk around. But I will normally have to check on her every 10 minutes, 15 minutes or so*' (Jack, 16)

An important consideration was to understand if young carers needed support with their caring role. For some young carers, support was available from other family members, either in the home or from extended family:

> *'My dad helps a lot of the time. Or I talk to my boyfriend, to make it easier'* (Rachael, 18)

> *'My dad and my nan helps'* (Gemma, 17)

> *'It was nurses who came out at night and they stopped over, but now it's my family who do it. So my grandad does the weekend, my cousin does two days a week and my nan does one day a week'* (Laura, 18)

Likewise, practical support came from a variety of sources, not just from family, and some of the participants welcomed support from paid carers, e.g. Daryl, who stated that:

'*Knowing there's people there to help, like the carers who come in...that helps'* (Daryl, 11)

However, it is also important to recognise that although having support from others may reduce the time and physical effort spent on caring, it does not necessarily equate with a reduction in overall impact. Sophie, who was not part of a dedicated young carers group, provided a rich and powerful narrative of the impact of having a rota of paid carers in the family home, which appeared to be triggered by the arrival of a carer to the home during the interview:

'It was quite difficult when I was younger to get over the fact that there was carers in my house. Sometimes when you're talking to your parent and then they walk into a room, the carer, and you have to stop what you're saying [...] Sometimes they come and sit with you at the dinner table while dad's getting (sister) to sleep. It's like a stranger in your house. How can you be yourself with a stranger in the house? Sometimes it can be very annoying. It can be <u>very</u> annoying' (Sophie, 13)

The emotional impact Sophie alluded to demonstrates the difficulties that may be experienced by all members of a family, not just those identified as young carers. Similarly, one member of the focus group reported that:

'We do have carers in, but my dad...stresses a lot when other people try to help him, so it's my mum, but I need to help my mum as well as help him' (FG Participant)

This juxtaposition illustrates the need to consider the impact of illness or disability on the whole family. Karl's account of caring for his brother highlights the difficulties he sometimes faced:

'*He has these little angry, tantrum kind of things...I think if I knew how to handle situations like that properly, it would help. Like learn more about his actual disability*' (Karl, 17)

Likewise, Cory spoke about how understanding more about his brother's medical condition might be helpful:

'To (know how to) deal with him when he's angry' (Cory, 11)

Another way in which practical support could be useful came from some of the participants accounts of learning first aid, in order to help their family member in case of an emergency (Jack, Laura and Sophie). Similarly, this could extend to include making a plan of who to contact if faced with a challenging situation. However, Jenny's experience of not being offered practical training or support illustrates how young carers needs are sometimes not included when considering the whole family:

> *'When they came around [social workers] they took my dad on a course and they helped him a lot, but there was nothing for me really'* (Jenny, 15)

Similarly, Daryl suggested that training in how to use some of the medical equipment in the home would benefit the support he could give to his mother when caring for his brother:

> *'And I try to help my mum, that can be hard. Trying to remember what things do and what they're for. Like if I didn't know what they did (machinery) and my mum needed some help, I'd find that hard'* (Daryl, 11)

The key issues identified for this sub-theme were around challenges providing care and the support or training offered to young carers to help in their caring role. These included the difficulties in establishing how much time was spent caring, how much support (if any) was provided to help young carers in their situation, difficulties in understanding how the illness or disability affected their family member, and how practical training was useful to help increase confidence and skills in providing care and support.

As described in Chapter Four (Methods), existing literature was revisited to ensure that issues previously reported as important in the published evidence base, were included in the development of the items for the Delphi survey. This approach ensured that any issues not raised by participants in this study were included so the Delphi survey was well informed and not limited by the sample size. This highlighted that in addition to the key issues identified above, a need for support with financial matters was indicated by Aldridge et al. (2016). It was noted that some young carers in their study wanted to be able to make more informed decisions about money management, budgeting and, in some cases, other financial or

practical support available for their loved one (e.g. making benefits claims) which could help to improve their independence and quality of life. Furthermore, in a study by the Children's Commissioner (2016), young carers chose their top three service requirements as to have: someone to talk to; support in making an emergency or crisis plan, and mental health support.

Altogether, nine items were developed for the second round of the Delphi survey for this sub-theme, as illustrated in Table 17 below.

Table 17: Understanding the Caring Situation

How important is it to ask the young person...	
1	...how long they have been caring for someone in their family?
2	...how much time they spend on average caring each day/week?
3	...if they have support from another adult in the home?
4	...if they need support to continue their caring role?
5	...if they need practical support or training to help them provide care?
6	...if they need support with financial matters, e.g. benefits, housing?
7	...if they want or need information about their family member's condition/disability?
8	...if they feel included in support decisions about their family member?
9	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?

5.5.2 Sub-theme 2: Details of the Care Provided by the Young Person

This sub-theme follows on from understanding the care situation. Most of the participants talked about the practical ways in which they supported their family member needing care, for instance Noah, who said he would:

> *'Clean, cook, feed the pets. I have to walk by her down the street because she has these little dizzy spells when she's going all wobbly. She starts to fall over so I want to be next to the road in case she falls in front of a car'* (Noah, 17)

Similarly, Jack listed the various ways he provided support:

> *'Washing up, cleaning, tidying, putting pots away, ironing, washing clothes and stuff, drying. Just stuff to make sure it doesn't turn into a bombsite'* (Jack, 16)

Sometimes, support in the home extended into helping with personal care:

> *'Sometimes when she's in a really, really, bad state she'll need help getting washed and dried and stuff in the bath. She'll need help lying in her bed, getting dressed'* (Gemma, 17)

> *'I shower my mum, I dress my mum and dry my mum and all that'* (Rachael, 18)

This could be particularly challenging for some young carers, as illustrated by Jack, when talking of caring for his mother:

> *'She has to use catheters, stuff like that, on the toilet. So if she's stuck on there or if she feels faint on there I would have to go in [...] you don't really want to go in there. But if my sister isn't in then unfortunately I have to do that'* (Jack, 16)

Similarly, Joe spoke of the difficulties he experienced helping to support his mother with personal care:

> *'She has some days where she needs help going to the toilet. It can be horrendous, some days'* (Joe, 16)

As noted in the first chapter, one of the key principles highlighted in the Care and Statutory Guidance issued under the Care Act (2014), paragraph 2.49, is that "*children should not undertake inappropriate or excessive caring roles that have an impact on their development*." Therefore, it is important to consider what might be deemed inappropriate and/or excessive as part of the caring role. In addition to providing personal care, this may include tasks that on the surface appear innocuous, but could have potentially catastrophic ramifications for young carers and the family member they care for. Several of the participants in this study were responsible for administering medication, e.g. Poppy who said that one of her tasks was to '*do the tablets',* and Rachael who said:

'I make sure my mum has got all her medication and everything like that. I get up at 2 o'clock (in the morning) to give my mum her medication and then I go back asleep for a little bit. Then about 6...' (Rachael, 18)

However, understanding the context is important, and for those young carers who have incorporated providing practical support into their lives for a long time, it may be less alarming than first appears, as elucidated in a matter of fact tone by Sophie:

'Some days you think she's good (sister) and then you have to jump in the back of the car on the motorway and do an emergency trachy tube change, because your mum is driving' (Sophie, 13)

Undertaking practical tasks is not the only type of support young carers provide, and one of the participants in the focus group clarified the importance of exploring all aspects of the caring role:

'Some people might think it's just helping and stuff, but it actually isn't. It can be an awful lot more than that' (FG Participant)

One of the ways this may manifest is through providing emotional support. This can happen through keeping their family member company or by offering reassurance or a listening ear, as illustrated by Ellie:

'When she starts to panic when she forgets, I tend to calm her down by giving her a hug' (Ellie, 17)

In some cases, emotional support can be used to relieve pressure on an ill or disabled parent by acting in loco parentis and providing care for siblings. In these cases, it may also affect the young carer's attendance and punctuality at school, as discussed by Jenny:

'I have to take my sister to school in the mornings and pick her up after school because my mum can't make the journey' (Jenny, 15)

Caring for siblings who have an illness or disability themselves can also be difficult and time consuming, and Bianca demonstrated the patience needed when looking after her younger brother:

> *'You have to simmer it down – you get him his comforts. You just have to sit there for a good hour and just lower it down, you just have to calm it down'* (Bianca, 17)

Similarly, Daryl highlighted the complex skills he had acquired in order to help support his brother:

> *'He's got loads of machinery and things. He has a ventilator and needs checking all the time to make sure he's okay. Like if his tracheotomy fell out, I'd put it back in and stuff like that. And I switch his feed pump off too'* (Daryl, 11)

One participant reported she felt obliged to attend appointments, in case her family member forgot or did not understand what had been said. Gemma described her role in caring for her mother as being like:

> '*Literally her notebook. Her living notebook...she'll forget within five seconds. She's like a goldfish'* (Gemma, 17)

Although she laughed as she spoke, it was clear that she felt responsible for her mother's care and treatment. Similarly, Laura reported:

> *'I take phone calls because she can't hear on the phone. When we go out to appointments, I'll repeat back to her, so she understands what they're saying'* (Laura, 18)

The key issues identified for this sub-theme were surrounding the tasks involved in providing care. Participants spoke of what their caring role entailed and how they carried out the various tasks. This included practical, personal or emotional care for the family member who needed support, but also in some instances this extended to caring for siblings in order to assist their ill or disabled parent. These findings are similar to those previously reported in existing literature. Furthermore, Aldridge et al. (2016) highlight the often physical nature of providing care, such as lifting or assisting with mobility, e.g. physically helping the family member move around the house or when outside, or providing therapeutic rubs or massages to ease physical symptoms of pain.

In total, nine items were developed for the second round of the Delphi survey for this sub-theme, as illustrated in Table 18 below.

Table 18: Details of the Care Provided by the Young Person

How important is it to ask the young person...	
1	...about the type of things they do to help in their caring role?
2	...if they are providing emotional support, e.g. keeping company or comforting?
3	...if they are helping with personal care, e.g. washing, dressing?
4	...if they are helping with practical household tasks, e.g. cleaning, laundry?
5	...if they are providing physical support, e.g. lifting, moving?
6	...if they are giving medication to the person they care for, or checking it has been taken?
7	...if they are attending appointments with the person they care for?
8	...if they are looking after siblings?
9	...if they are undertaking tasks they don't want to do?

5.6 Theme Two: Carer's Health and Wellbeing

The second overarching theme relates to the young carer's physical and emotional health and their overall wellbeing. It considers whether the young carer has any current support needs for themselves, or whether they anticipate any increasing issues in the future that could impact on their health, social wellbeing, education or future career aspirations.

5.6.1 Sub-theme 3: The Young Carer's own Health and Social Wellbeing

As discussed previously, undertaking a caring role can negatively impact a young person's health and wellbeing in a number of ways. However, even when their health is not directly compromised, there may be an underlying potential impact present, as illustrated by Gemma:

> *'This one time she got in the bath and tried to get out on her own and it failed. She slipped and cracked a rib and she couldn't do anything. I literally legged it up the stairs, and picked her up. My mum's twice the size of me. You know what I mean? I picked her up!'* (Gemma, 17)

Likewise, for Rachael:

> *'On college days I have half an hour dinner. I run home, make sure everything is okay at home, so I hardly get a dinner time. If my mum falls over, like she did a couple of days ago, me and my friend had to go home and help her up'* (Rachael, 18)

However, the greatest impact young carers alluded to related to their emotional health and wellbeing. Several of the participants in the present study talked of the stress they felt (Rachael, Ellie, Bianca, Noah), and Jack demonstrated the continual and often relentless nature of worrying:

> *'You're constantly worrying about, what if this happened...what if that happened...what if this happened?'* (Jack, 16)

Similarly, Laura alluded to the strain of constantly being alert to any changes in her mother's health:

> *'Even when I'm in bed I still sit up and listen out for my mum's breathing'* (Laura, 18)

It was evident from speaking to participants in the interviews and focus group how much love and concern they felt for their family, and Joe illustrated how caring for his mother affected him emotionally:

> *'On bad days it really does affect how I feel, because – it's really cringy, actually thinking about it - I care about my mum a lot. I'm seeing her, when she is on a bad day...it absolutely breaks my heart'* (Joe, 16)

One member of the focus group explained their feelings for their sibling by stating that:

> *'Sometimes I put my brother before myself - sometimes I can worry more for him than for myself. It's so hard...'* (FG Participant)

Similarly, Laura spoke about how witnessing her brother's distress was often more harrowing than dealing with her own feelings:

> *'It can be difficult and it's upsetting sometimes, watching. Like when my mum gets rushed to hospital it's upsetting for me, but it upsets me more because*

my brothers are watching... and it upsets them as well. She had a tracheotomy done in her throat and when she had that done we got told that she might not be coming out of hospital. So now, every time she goes in it stirs that she's not going to come home' (Laura, 18)

Some participants revealed they had friends or family members they could speak to when they were struggling with their emotions:

'I talk to my boyfriend [...] because obviously he'd listen to me and then I just let everything out' (Rachael, 18)

'My grandmother were there, so I could talk to her if I needed' (FG Participant)

For others, support came more from outside sources:

'I also get a lot of help like that from (support worker). I can arrange to go out and get a coffee or something, talk things out I guess' (Jack, 16)

'When I was about 14 I had a counsellor to talk to about it. There used to be a youth centre, I used to go there and they sorted it for me. So I had a counsellor there and I had her for I think it was two or three years' (Laura, 18)

Several of the participants additionally talked of different coping strategies they sometimes used when they felt particularly overwhelmed by their emotions:

'I go upstairs in my room, calm down, watch a DVD or something like that' (Rachael, 18)

'I try and - this sounds really bad - I try and blank it out quite a lot of the time. I do try and blank it out. But it always creeps its way back in' (Jack, 16)

'If things ever go bad, or if anything happens, then I just decide...I need a break for 10 minutes, half an hour, an hour, I'd go and sit upstairs on my X Box' (Joe, 16)

When discussing their social wellbeing, some participants reported they found it particularly challenging to find time to socialise, such as Noah, Poppy and Jenny, who all reported that not being able to go out was '*probably the most difficult challenge'.* For others, it was less about the lack of time and more about the quality. In Ellie's case, she confirmed how she also

wanted more quality time with other members of her family, and hinted at the loneliness she sometimes felt:

> '*I don't get to spend time with my mum and dad as they are (busy) looking after my brother or nan. Which isolates me sometimes...'* (Ellie, 17)

Feeling isolated was also felt acutely by some participants in the focus group, who found it particularly difficult to establish and maintain friendships with non-caring peers. One participant highlighted how he:

> *'Find(s) it hard to fit in with all the people at school because they're enjoying their life [...] it's really hard, because you don't know what to say or do in them situations, to fit in with other people'* (FG Participant)

And Joe, who evocatively recalled that*:*

> *'When it comes to friendships and things like that – social activity - I have nothing to talk about. I have nothing to relate to my friends about*' (Joe, 16)

Young carers who were part of a dedicated young carers' support group, were unequivocal in praising the importance of the groups to their social wellbeing, and for the peer support the groups offered. For some, it gave them the opportunity to take part in activities they otherwise would not have the chance to engage in, such as trips to adventure parks or festivals. Most of the participants valued the solidarity of being with other young carers who understood the challenges of caring, as illustrated by Noah:

> *'I didn't want to come at first because I had anxiety and everything like that. I couldn't face everyone. I was also worried about mum. But I came one day and then I was just myself. When I came here just knowing that there were more people in my situation's just helped me so much'* (Noah, 17)

> *'It definitely helps – going out the house and seeing people. It's a little bit of social interaction. These guys all understand it. People get how tiring it can be. It's brilliant*' (Joe, 16)

However, it is important to note that the findings also suggested some young carers, particularly those not attending a dedicated young carers' group, preferred not to access peer support from other young carers. Liam revealed he would:

> '*Rather speak to my mates, to be honest*' (Liam, 14)

Likewise, Callum felt that:

> *'Going to college and seeing friends who don't have to look after their parents helps'* (Callum, 16)

And Emma, who said that:

> *'I go to choir. Gives you something else to do'* (Emma, 12)

The key issues identified for this sub-theme confirmed that both physical and emotional health could be compromised by the tasks undertaken by the participants. Moreover, although some participants wanted to spend more quality time with their families, some also expressed a desire to have a break from caring, with more opportunities to socialise with friends and peers. This was mainly through dedicated young carers' groups but could also be from spending time engaging in other activities. Existing literature reports similar findings to those in this study, and also highlights that some young carers may additionally feel frustration, guilt and obligation towards their family member needing care (Bolas, Van Wersch and Flynn, 2007).

Altogether eight items were developed for the second round of the Delphi survey for this sub-theme, as illustrated in Table 19 on the next page.

Table 19: The Young Carers Own Health and Social Wellbeing

How important is it to ask the young person...	
1	...if they need support with their physical health?
2	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?
3	...if they have a friend or family member they can speak to or contact for help or support?
4	...if they spend time with their friends?
5	...if they spend time with their family members?
6	...if they want a break or time away from their caring role?
7	...if they attend/receive support from a young carers' service?
8	...if they need help accessing a group, or any other clubs in their schools or local community?

5.6.2 Sub-theme 4: The Young Carer's Identity and Self-Esteem

This sub-theme follows on from the last and explores the participants' self-perception of their status as carers, and whether they felt this was understood by others. As highlighted in the previous sub-theme, some of the participants chose not to access support from young carers' groups. This raises the question of whether some young carers may feel uncomfortable being identified or described in this way, such as Bianca, who said:

> *'I don't particularly like it, but it's not really my choice'* (Bianca, 17)

Conversely, Noah highlighted the importance of respecting a young carer's decision about whether or not, when, and how they choose to reveal their carer status:

> *'You have to actually listen to them [young carers] and acknowledge them! This is what you have to say!'* (Noah, 17)

However, Jack's reluctance to refer to himself as a young carer appeared to be related more to the semantics of the words 'care' and 'carer':

> *'I don't necessarily see a young carer as someone who cares for someone. I don't see it as that. Because when you say that, it sort of outlines that everybody else who isn't one, doesn't care. So I don't like saying it'* (Jack, 16)

For some young carers in the focus group, there was confusion about whether their non-caring peers understood their caring role, and one participant illustrated this lucidly:

> *'It seems like they're being sarcastic, but you don't know if they are or not, when they go like, say, for example, quite a lot of people say: 'how's your mum?' and everything, and I don't know if they're...they're <u>really</u> asking, or are they just trying to take the micky? I don't really know'* (FG Participant)

Likewise, another member of the focus group explained that when their non-caring friends asked them to socialise outside of school, they:

> *'Kind of keep quiet, because, when you're, when they say are you coming out? When you have to tell them, no, you have to look after someone, you're struggling - they just make fun of it, don't they?'* (FG Participant)

And another participant reported that:

> *'Like only my friends know about it. Like I don't tell anyone else because I don't know what they'll think'* (Poppy, 16)

However, a lack of understanding appeared to extend to peers who were also carers. One participant gave an evocative account of a situation when another young carer friend came for tea and was distressed by meeting her profoundly disabled sister:

> *'I thought because she [friend] was in the young carer group it would just be normal. We went upstairs and she was crying. I don't know what you're supposed to say in that situation. You're so young and you're having someone coming to your house and crying...my mum went to her 'it's okay she (sister) won't hurt you' and she went, 'oh I know, I'm not worried about that. I just don't want to catch anything'* (Sophie, 13)

One member of the focus group tried to explain how they felt people generally fell into one of two categories, those who understand their status and those who do not:

> *'Well, there's two types of people, when you tell them, like there's some people that you tell and then they'll just be like, oh, okay, whatever, like don't make anything of it. But then there's people who ask too many questions [...]*

Like they might just feel sorry for you [...] Or they might just think you're weird, or something. So you're better off just keeping it to yourself' (FG Participant)

This leads to questions about whether young carers also feel uncomfortable or confused about telling professionals, or those in authority, about their caring role and home situation. For Jack, there was a sense of frustration when he recalled a visit to a pharmacy to collect medication for his mother:

'They didn't take me seriously at the pharmacy last year when I was getting a lot of prescriptions like morphine and stuff. They didn't take me really serious there' (Jack, 16)

Similarly, Callum explained that:

'I don't talk about it in school. I don't think my college knows about my situation, it's kind of personal. I mean they could ask about being a young carer, but if they asked who I care for, I wouldn't tell them because my mum wants it, like, within the family' (Callum, 16)

Callum's decision not to reveal his young carer status appeared influenced more by family loyalty than by confusion, or difficulty speaking to college staff about his caring role, and again highlights the shroud of secrecy many young carers live under. For Laura, this had also been the case initially, although she now felt more able to speak up:

'When I was younger I didn't really tell anybody about it, I kept it to myself. Now I've grown up I tell people, but only if I know I can trust them, because it's a family thing to talk about...it's got nothing to do with anybody else' (Laura, 18)

Perhaps being one of the older young carers, at 18, made a difference to Laura feeling able to talk about her situation, albeit on her own terms. However, it also connotes a sense of secrecy and wariness some young carers may experience.

The key issues identified for this sub-theme were about the identity of young carers, and recognition of the caring role participants undertook. Lack of understanding and, in some

cases, confusion surrounding other peoples' motives for asking about their situation, led to a reluctance by some participants to talk about their role or reveal their status. Some did talk about it to others, but often qualified their comments by stating this was usually only with selected people they could trust. Existing literature confirmed that young carers had good reason to be cautious, e.g. in a study by Moore et al. (2009), 45% of young carers (n=51) could identify times when they had been directly teased or assaulted because of their caring role. Moreover, a study by Aldridge et al. (2016) highlighted that some young carers struggle to speak to others about their role and may benefit from having an advocate who can speak on their behalf.

Altogether, five questions were developed for the second round of the Delphi survey for this sub-theme, as illustrated in Table 20 below.

Table 20: The Young Carers Identity and Self-Esteem

How important is it to ask the young person...	
1	...whether they see themselves as a young carer?
2	...if they feel recognised and supported by others for their caring role?
3	...if they feel bullied or stigmatised by others for their caring role?
4	...if they want or need support speaking to people about their caring role?
5	...if they have someone who can speak on their behalf, if necessary?

5.6.3 Sub-theme 5: Education and Future Plans

The final sub-theme relates to young carers' education, their experiences at school or college, and their future plans beyond compulsory education. Attendance and punctuality can both be affected by the caring role, but there can also be difficulties with concentration and engagement in lessons, as illustrated by Noah when talking about caring for his mother:

> *'It was affecting school. I would be worried at school in case something would happen. I started doing less homework [...] I started taking time off school, so I could stay at home and obviously help her'* (Noah, 17)

Part of this may, of course, be due to young carers' reluctance to reveal their carer status, as discussed previously. Noah highlighted the difficulties he experienced at school by discussing his experience further:

> *'They didn't know [about caring role] at first, but then it got a bit too dramatic, so I had to basically tell them and then they tried to fix around it'* (Noah, 17)

Likewise, Laura spoke of the importance of having a named member of staff at college who could be approached for support when needed:

> *'When I started college they asked if there's anyone you care for and if there are any situations. So my personal teacher in college knows about it as well and she knows if there's anything wrong, then I can just get in touch with her and let her know and she'll sort it out for me'* (Laura, 18)

However, not all participants felt their teachers would be supportive, even if they were made aware of the situation at home, as Joe's account suggests:

> *'Teachers? (*laughs) That's a funny one. I think they pretend to know all about it, because if they open up and say that they don't have a clue, they might think that they're potentially offending someone - because I know one of my teachers doesn't have a clue about it and I know that he's too - not scared of asking questions, as such. He's more scared of offending me with questions'* (Joe, 16)

Moreover, making staff aware of their caring role and situation at home may be difficult for some young people, and one participant talked of how they had struggled with this:

> '*My teacher doesn't even know (about caring role) even though I have told and hinted to them about it'* (Ellie, 17)

Similarly, several participants felt they may not have been taken seriously by teachers:

> '*They think it's an excuse'* (Harry, 13)

> *'College don't understand. Because they're like 'get off your phone'. I'm like, 'it's my mum'. 'Tell your mum that you're in a lesson'* (Rachael, 18)

'Sometimes you've got no time to do your homework, because your caring for your - and then they don't understand that. They just think it's an excuse' (FG Participant)

Sophie recalled a particularly distressing experience, that perhaps could have been avoided if her teacher had shared information with other staff members about her caring situation:

'There has been mistakes in my school in year 7 - [sister] had been rushed into hospital the night before, so I was...I stayed at my aunties, and I didn't have any books or anything. It was all just go, go, go. I didn't have my books, I didn't have my homework. She [science teacher] gave me a detention and shouted at me and sent me out the classroom' (Sophie, 13)

Some participants had found it difficult knowing which member of staff to approach, and Bianca suggested there was also inconsistency amongst staff, as she stated that she knew of:

'People who are young carers and go to the same school [as me] and they had to go from teachers and teachers and teachers to get to a certain position' (Bianca, 17)

Conversely, some participants had received support and understanding from staff at school who were aware of their caring role, such as Jenny, who stated:

'You get longer to do homework. If they're giving homework they give me like an extra week to do it' (Jenny, 15)

Similarly, Noah was given extra time for homework and also had the opportunity to phone home to speak to his mother during the school day for reassurance, if necessary:

'They gave me a couple of days on homework [...] They said, oh yeah, you can ring from school if I need to get in touch with her, to make sure she's okay' (Noah, 17)

Jack's teachers had been particularly supportive of trying to understand and accommodate his needs, and he spoke about how:

'My teachers actually started to help me. They started to give me emails. So I was doing it (homework) at like eight o'clock at night and my teacher was

typing me, like why don't you try this instead? So they went out of their way from their families to actually help me' (Jack, 16)

However, not all schools had support systems in place. Rachael suggested several initiatives that she thought would be particularly beneficial for her:

'Maybe extensions on some of my assignments or something? I can ask them for a longer dinner, to actually get something to eat, something like that' (Rachael, 18)

When it came to future aspirations beyond compulsory education, some participants found it difficult to foresee a future when they would not be caring, but some had been able to consider it, albeit either tentatively, as considered by Rachael:

'My mum's got, and my brother's got a lifelong illness, so no, not really. It might get easier as I get on, because my brother will grow up and then kind of get a bit more mature. Then my mum will have my older brother as well' (Rachael, 18)

Or privately, as implied by Jenny:

'I've got an idea of what college I want to go to, but I haven't said to my parents about it yet' (Jenny, 15)

However, one participant spoke of how she kept motivated to help her parents care for her brother, as she knew she would not be able to once she started university:

'I keep myself motivated as I know I'll be able to have some time to myself when I'm in university' (Ellie, 17)

The key issues identified for this sub-theme were the difficulties some young carers faced when attending and engaging with school or college. Particular problems appeared to stem from a lack of awareness or understanding from staff, often compounded by the participant's reluctance to share pertinent information. Some helpful factors were identified, and future aspirations were discussed, although many of the participants found it difficult to envisage how this might manifest. Existing literature recommends that careers advisors in schools are

trained to be aware of the challenges young carers face when making decisions about post-compulsory education, so that they can offer relevant advice and support (Barnardo's, 2017).

In total, six questions were developed for the second round of the Delphi survey for this sub-theme, as illustrated in Table 21 below.

Table 21: Education and Future Plans

How important is it to ask the young person...	
1	...if there is a named staff member at their school/college for young carers?
2	...if they want or need help to make staff at school/college aware of their caring role?
3	...if there are specific needs they have in school/college, e.g. extra time for homework?
4	...if there is anything that could help reduce stress/anxiety at or about school/college?
5	...if they need additional advice/support about future education or career options?
6	...if they intend to continue in their caring role after leaving school/college?

5.7 Reviewing and Refining the Survey

Questions in the survey were reviewed and discussed with the supervision team throughout the analysis period. Initially there were 75 potential questions, or items, for consideration across the data set, although some of these were duplicates, or clearly overlapped between sub-themes. Some of the items were reduced by eliminating duplicates, or combining similar items to form one item, and some were removed as it was evident they would be included in other sections of the CAT-YC, such as the demographic details section. This resulted in 36 items developed altogether across the five sub-themes, or topics.

A separate demographics section was added to the survey, to capture relevant information about the participants. Additionally, a final section was added, asking participants whether they felt it was important for young carers' needs to be assessed, and if so, how often. This was important to ascertain as findings from the data for this round indicated that many of the participants either could not remember if they had ever had their needs assessed (Noah, Callum, Sophie, Daryl and Laura), or recalled it being between one and six years ago (Joe, Jenny, Liam, Rachael, Gemma and Jack). Participants for the next round of the survey were

also asked to choose from a multiple-choice list of who they felt should carry out screenings and assessments. Finally, participants were asked to rank the five sub-themes according to their perception of least to most important (Knighting et al. 2015, 2016).

The survey was then sent to gatekeepers at each of the three young carers' groups who would be participating in the consensus group meetings, asking them to obtain feedback from several potential participants on clarity and approximate time taken to complete the survey. Feedback received from one of the groups drew attention to one of the questions being ambiguous, and a suggestion was made and implemented to split it into two questions (sub-theme 3, items 4 (...*if they spend time with their friends*?) and 5 (…*if they spend time with their family members?*) which were originally one item). Changes were made to the survey accordingly and approved by the relevant ethics committees prior to its launch in June 2018.

5.8 Summary

This chapter has provided an explanation of how data from phase one of the study were thematically analysed and supplemented with findings from data in existing literature, to form items for the second round of the Delphi survey in phase two. These items were set out in the final section in each of the five sub-themes, or topics. The role of the supervisory team and potential participants in reviewing and refining the items before the survey opened was explained. As stated in Chapter 4 (Methods), the survey was developed for online completion by professionals and young carers aged 16-18, and for paper completion at small group meetings for young carers aged 11-15. The next chapter sets out findings from analysis of rounds two and three of the survey, and the role and findings of the national expert panel in developing the final items for the CAT-YC.

Chapter Six

Findings from Phase Two

6.1 Introduction

This chapter contains a detailed explanation of the process, analysis and findings from rounds two and three of the Delphi survey and the expert panel. The chapter starts by providing a visual overview of the Delphi rounds and number of participants, in the form of a flow chart. It then briefly recounts on how findings from phase one of the study replaced the first round of the Delphi survey. The recruitment process, demographic details, data collection, quantitative analysis and findings for rounds two and three will be presented separately, as in previous Delphi studies (Jünger et al. 2017). However, qualitative analysis of the data from the open text comment boxes from both rounds will be presented together as similar themes were identified in each. Finally, the results and findings of an expert panel in reviewing and finalising the top ranked items will be discussed. The chapter concludes with a summary of the top ten items for inclusion in the pilot version of the CAT-YC.

6.2 Overview of Delphi Rounds

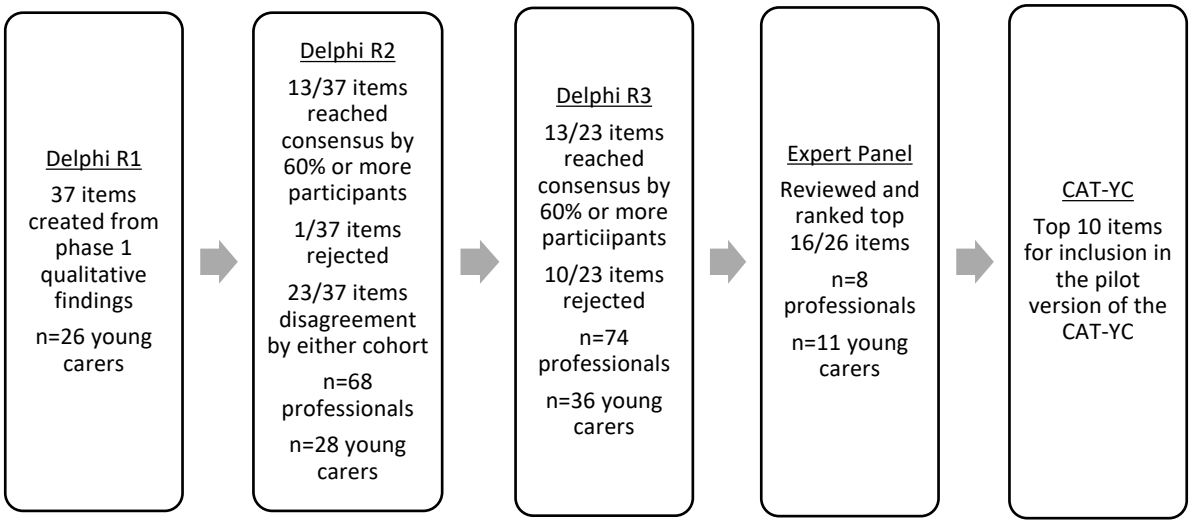


Figure 12: Flow Chart of Delphi Survey Rounds and Number of Participants

6.2.1 Delphi Survey Round One

As reported in the previous chapter a modified Delphi approach was used, with the findings and development of items from phase one forming and replacing the first round of the survey

(Keeney, Hasson and McKenna, 2011; Keeney, 2015). Data from 26 participants were thematically analysed and considered alongside existing literature to develop 37 items for inclusion in Round 2 (R2) of the Delphi survey. The items were developed from two over-arching themes: the caring role within the current situation; and health and wellbeing. These themes represented five sub-themes, or topics, with each topic containing between five and nine items. Table 22 in Appendix 10 contains the full list of items within their topics.

6.3 Delphi Survey Round Two

The survey developed for R2 comprised of three sections: A (demographics); B (survey items); and C (CAT-YC future use and development) and was based on similar design principles to the original CAT survey (Knighting et al. 2015, 2016). Section A was differentiated according to whether the participants were young carers or professionals working with young carers. Young carers were asked their age, gender, ethnicity, geographical region, who they cared for, the medical condition of the person they cared for (if known), approximately how much time they spent caring in an average week and the length of time they had been a young carer. Professionals were asked their gender, ethnicity, geographical work location, job title and length of time they had been working with young carers. All participants were reminded that the surveys were anonymous and voluntary, as had been stated in the accompanying participant information.

Sections B and C were the same for both cohorts of participants. In Section B participants were asked to rate each item within the topics on a five-point Likert scale, from (1) being '*not at all important*' to (5) being '*extremely important',* for inclusion in the CAT-YC. Open text comment boxes were also included after each topic for participants to elaborate if desired. In Section C participants were similarly asked to rate from (1)-(5) how important they felt it was for young carers to have their needs assessed, and if so, how frequently they should be assessed, which professional(s) should use the CAT-YC, and finally to priority rank the five topics in order of importance to them.

Prior to launching the survey, a small pilot study was undertaken with professionals and young carers (n=6) at organisations who had taken part in phase one of the study, as

recommended for Delphi studies by Novakowski and Wellar (2008). Feedback from young carers led to an additional demographic option of '*prefer to self-identify*' in the gender category of Section A. Feedback from professionals led to a minor modification of the question in Section C '*As situations can change over time, how often do you think young carers' needs should be assessed as a minimum?*' to become '*As situations can change over time, how often do you think young carers' needs should be reviewed as a minimum?*' . It was also estimated by the professionals that the survey would take approximately 20 minutes to complete. A copy of the questions for 16-18 year old young carers in the R2 survey is included in Appendix 11 as an exemplar.

6.3.1 Round Two Data Collection (Professionals and Young Carers 16-18)

As in phase one of the study, a purposive sampling approach was undertaken to recruit participants (Green and Thorogood, 2014; Bryman, 2016). Altogether, 142 organisations known to work with young carers were contacted by email in June 2018 and asked to cascade information about the study, together with an invitation for eligible staff members and young carers aged 16-18 to take part in the online Delphi survey. The invitation contained a link to the survey, which was created via SurveyMonkey® (www.surveymonkey.com) and posted online with instructions on how to complete it. The survey was also advertised on the social media site Twitter; therefore, it is not possible to know the exact number of potential participants who may have considered taking part. However, analytics on SurveyMonkey® showed that the professional survey link was clicked on 90 times and the link for young carers aged 16-18 was clicked on 16 times. The survey remained open for four weeks and data were collected from 68 professionals and 10 young carers aged 16-18, which equates to 74% of those who accessed it overall.

6.3.2 Round Two Data Collection (Young Carers 11-15)

As previously reported in Chapter Four (Methods), young carers aged 11-15 were not approached to take part in the online survey, due to concerns that web-based surveys are not recommended as appropriate for children (Greene and Hogan, 2005). Gatekeepers at the organisations who took part in phase one of the study were contacted to arrange a suitable time and place to facilitate small group meetings for participants, with the aim of having 6-8

participants at each (Goodman and Evans, 2015). Three meetings took place in June-July 2018 to coincide with the online survey and each meeting lasted approximately 60 minutes. Participants were given coloured packs of laminated cards representing each of the five topics in Section B. The items on the cards were read out and participants were asked to individually rate each item in the same way as in the online survey. Stickers were used to record their answers and they also completed paper copies of Sections A and C, as in Figure 13 below. After each topic and at the end of the process, the items and topics were discussed as a group. Comments were noted and added to each pack before data were manually entered into SurveyMonkey® prior to analysis. Altogether, data were collected from 18 young carers aged 11-15.

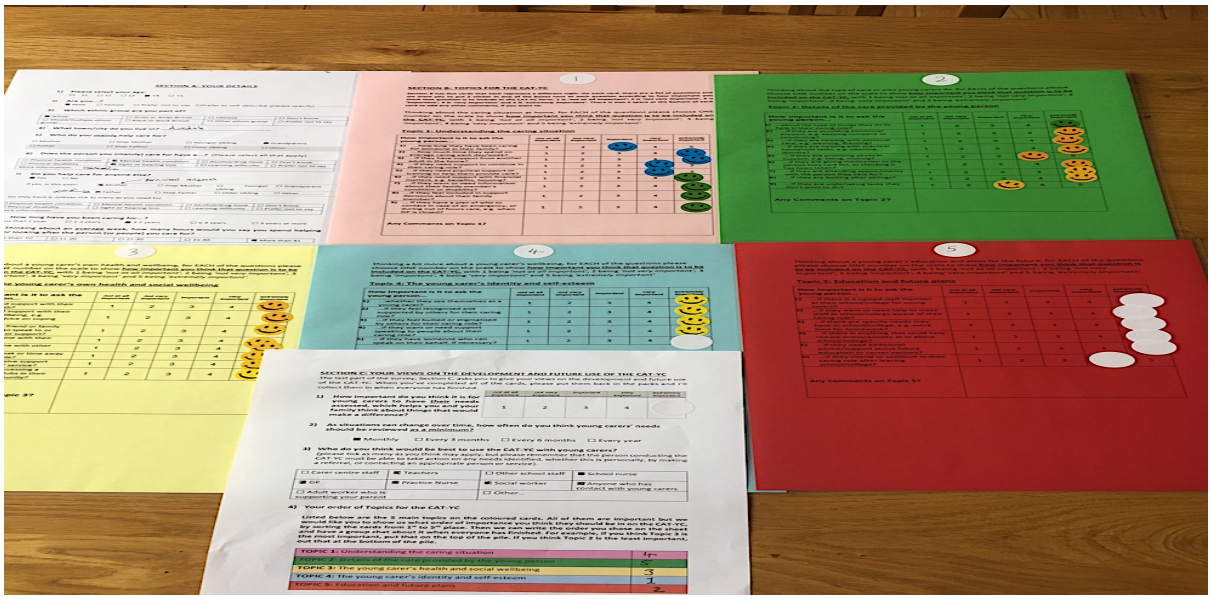


Figure 13: Data collected from participants aged 11-15

6.3.3 Data Analysis Round Two

Quantitative data from the survey were entered into IBM SPSS Statistics, Version 25 for analysis (Armonk, NY: IBM Corp, 2018). Data from the 11-15 year old participants were combined with those from the 16-18 year olds who took part online, and were analysed as one data set. Data for Section A were analysed using descriptive statistics to describe the participants according to the demographic information gained (Bryman, 2016). Data for Sections B and C were analysed using measures of central tendency, frequency and levels of dispersion to provide results on the rating of items, participants' views on the future

development and use of the CAT-YC, and ranking of the topics (Oppenheim, 2000; Munro, 2005; Field, 2013). Qualitative data from the open text comment boxes were thematically analysed, as reported in Chapter Four (Methods).

6.4 Results and Findings Round Two

In total, 96 participants completed the R2 survey, comprising of 68 professionals and 28 young carers aged 11-18. An additional four professionals completed the demographics section of the survey but not Sections B or C, therefore their information was removed before analysis. Results from Section A of the survey will be presented separately for each cohort, then the results of Sections B and C will be presented together. For the purposes of this thesis, percentages involving people will be rounded to the nearest whole number, therefore may not add up exactly to 100% (Welkowitz, Cohen and Lea, 2012).

6.4.1 R2 Section A Participant Profiles (Professionals)

The professionals consisted of a range of staff working either directly or indirectly with young carers, in the paid and voluntary sectors. The option selected most often by professionals was young carers' support workers (30), followed by teaching assistants (six). Two of participants were social workers, one selected the option for learning mentor/pastoral staff and one selected youth worker. Many participants additionally qualified their position by adding 'manager', 'co-ordinator' or 'volunteer' in the additional comments box. Two participants stated they were nurse consultants; one participant was a psychologist and one was a psychotherapist. However, although there were options for G.Ps, school nurses, practice nurses and teachers, none took part. It is not possible to know the exact length of time the participants had worked with young carers, but 41% stated it was nine or more years. Table 23 on the next page displays all of the demographic characteristics of the professional participants.

Table 23: Demographic Profile of Professionals R2

Characteristics	n (%)	Characteristics	n (%)
Gender		**Region of Work**	
Male	9 (13%)	Greater London	4 (6%)
Female	58 (85%)	South East	7 (10%)
Prefer not to say	1 (2%)	South West	4 (6%)
		West Midlands	4 (6%)
Ethnicity		East Midlands	2 (3%)
White British	59 (87%)	North West	21 (31%)
White Other	4 (6%)	North East	10 (15%)
Black/Black British	2 (3%)	Yorkshire and the Humber	3 (4%)
Mixed/multiple ethnic groups	2 (3%)	East of England	4 (6%)
Prefer not to say	1 (1%)	Wales	1 (2%)
		Scotland	3 (4%)
Length of Time in Role		Northern Ireland	2 (3%)
Less than 1 year	8 (12%)	Other	3 (4%)
1-2 years	9 (13%)	**Job Title**	
3-4 years	14 (19%)	Young Carers Support Worker	30 (44%)
5-6 years	6 (9%)	Youth Worker	1 (2%)
7-8 years	3 (4%)	Social Worker	2 (3%)
9 years or more	28 (41%)	Learning Mentor/Pastoral Staff	1 (2%)
		Teaching Assistant	6 (9%)
		Other	28 (41%)

6.4.2 R2 Section A Participant Profiles (Young Carers)

The average age of the young carers overall was 14.4, and they comprised of 21 girls and seven boys. The majority of participants (71%) were from the towns and cities in North West England where the small group meetings took place. The remaining participants were from the 16-18 year old category, who took part in the online survey. The majority of participants (18) primarily cared for their mother, five cared for their father, three cared for a sibling and two cared for a grandparent. The main reasons for their family member needing care were due to a mental health condition (57%), a physical health condition (39%) or a physical disability (32%). However, some participants selected more than one reason, therefore the percentages shown for that category in Table 24 on the next page are only an indication of

the prevalence of affecting health conditions. More than half of the participants (15) reported they provided care for 21 or more hours per week.

Table 24: Demographic Profile of Young Carers R2

Characteristics	n (%)	Characteristics	n (%)
Gender		**Town or City**	
Male	7 (25%)	Liverpool	6 (21%)
Female	21 (75%)	Sefton	4 (14%)
		Wigan	10 (36%)
Age		Knowsley	1 (4%)
11	2 (7%)	Bolton	1 (4%)
12	5 (18%)	Sunderland	1 (4%)
13	5 (18%)	Ripon	1 (4%)
14	4 (14%)	Coventry/West Midlands	2 (7%)
15	2 (7%)	Gloucester	2 (7%)
16	4 (14%)		
17	2 (7%)	**Main Care Recipient**	
18	4 (14%)	Mother	18 (64%)
		Father	5 (18%)
Ethnicity		Older Sibling	2 (7%)
White British	21 (75%)	Younger Sibling	1 (4%)
White Other	1 (4%)	Grandparent	2 (7%)
Asian/Asian British	3 (11%)		
Mixed/multiple ethnic group	3 (11%)	**Reason for Recipient Needing Care**	
		Physical Health Condition	11 (39%)
Length of Time in Caring Role		Physical Disability	9 (32%)
1-2 years	5 (19%)	Mental Health Condition	16 (57%)
3-4 years	12 (44%)	Sight or Hearing Loss	4 (14%)
5-6 years	6 (22%)	Learning Difficulty	4 (14%)
9 years or more	5 (15%)	Drug/Alcohol Dependency	1 (4%)
		Don't Know	1 (4%)
Hours Spent Caring Each Week		(**Some participants selected more than one reason for care*)	
Less than 10	6 (21%)		
10-20	7 (25%)		
21-30	7 (25%)		
31-40	3 (11%)		
41 or more	5 (18%)		

6.4.3 R2 Section B Findings

Descriptive statistics were used to explore the median and interquartile range (IQR) of the ratings of both young carer and professional cohorts and for the total sample, for each item within the five topics (Knighting et al. 2015, 2016). As discussed in Chapter Four (Methods), the criterion to accept an item in the Delphi survey was set for at least 60% of participants in both the young carer and professional cohorts to rate an item as equal to or greater than a median level of (4) '*very important'* on a five-point Likert scale. Accepted items were removed from the survey as they did not require any further rating, before proceeding to the next round. The criterion for rejecting an item was set at less than 60% of participants from both cohorts rating an item as equal to or greater a median level of (4). Those items which required re-rating due to disagreement between the cohorts, i.e. 60% or more participants from one cohort but not the other rating an item at a median level of (4) or higher, were retained for re-rating in R3 (McKenna, Hasson and Keeney, 2015).

The results from each cohort were tabulated separately and then combined into a larger table to show the number of participants, median and IQR, and percentage consensus levels for each of the 37 items within their topics. As reported earlier in Section 6.4, percentages have been rounded to the nearest whole number (Welkowitz, Cohen and Lea, 2012). Table 25 on the following page shows an example of how data findings were tabulated for one of the topics; the full table of results for all of the items and topics in this round are in Table 26, Appendix 12 of this thesis.

Table 25: Example from R2 Findings (Total Sample; Topic 3)

	TOPIC 3: THE YOUNG CARERS OWN HEALTH AND WELLBEING How important is it to ask the young person...	Total Sample (N)	Total Sample Median (IQR)	Total Sample Consensus [N (%)]	Profs (N)	Profs Median (IQR)	Profs Consensus [N (%)]	Young Carers (N)	Young Carers Median (IQR)	Young Carers Consensus [N (%)]	Criteria*
1	...if they need support with their physical health?	93	4 (2.00)	69 (74%)	67	5 (1.00)	60 (90%)	26	3 (1.00)	9 (35%)	RE-RATE
2	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?	93	5 (1.00)	84 **(90%)**	67	5 (0)	66 **(99%)**	26	4 (2.00)	18 **(69%)**	MET
3	...if they have a friend or family member they can speak to or contact for help or support?	93	5 (1.00)	74 (80%)	67	5 (1.00)	59 (88%)	26	4 (2.00)	15 (58%)	RE-RATE
4	...if they spend time with their friends?	93	4 (1.00)	76 **(82%)**	67	5 (1.00)	59 **(88%)**	26	4 (1.25)	17 **(65%)**	MET
5	...if they spend time with their family members?	92	4 (2.00)	61 (67%)	66	5 (1.00)	51 (77%)	26	3 (2.00)	10 (39%)	RE-RATE
6	...if they want a break or time away from their caring role?	92	5 (1.00)	76 **(83%)**	66	5 (1.00)	57 **(86%)**	26	4 (2.00)	19 **(73%)**	MET
7	...if they attend/receive support from a young carers' service?	93	4 (2.00)	65 (70%)	67	5 (1.00)	53 (79%)	26	4 (2.00)	12 (46%)	RE-RATE
8	...if they need help accessing a group, or any other clubs in their schools or local community?	92	4 (2.00)	64 (70%)	67	4 (1.00)	54 (81%)	25	3 (2.00)	10 (40%)	RE-RATE

**** If 60% met note MET, if disagreed note RE-RATE, if 60% not met note REMOVE***

Criterion to accept an item: at least 60% of both the young carer and professional cohorts rated an item as (4) 'important' or (5) 'extremely important'

Criterion for re-rating an item: if 60% of one cohort rated an item as (4) 'important' or (5) 'extremely important' but the other cohort did not, suggesting disagreement between the cohorts.

Criterion for rejecting an item: any items that did not meet the 60% criteria in both cohorts.

Only one item out of the 37 was rejected, as it did not meet the 60% consensus criterion by both cohorts. There was a consistently high level (81%) of consensus for rating the remaining items at a median level of (4) or higher by the professional cohort, but this level was much lower (54%) by the young carer cohort. The latter cohort rated 16 items at a median level of (3); 18 items at a median level of (4), and just three items at a median level of (5). Furthermore, the young carer cohort consensus levels were mostly in the 30s (n=8), 40s (n=8), 50s (n=6) and 60s (n=8), showing the low spread of consensus amongst the participants. This perhaps indicates that young carers may have been more discerning about what was important to them personally, whereas professionals may have rated the items based on their overall generic experience. Altogether, 13 items reached the criterion to accept an item and were therefore removed from the survey and set aside for later consideration. It is important to note that this did not mean they were the most important items for inclusion in the CAT-YC, merely that they had reached consensus first (Keeney, Hasson and McKenna, 2011).

Although comments from the open text comment boxes will be considered in more detail later in this chapter, several comments were made that resulted in slight changes to the wording of two of the remaining 23 items, to be sent out in R3 for reconsideration. In Topic 2, item 8 '*how important is it to ask the young person if they are looking after siblings'* was extended by adding '*due to a parent's poor health*' to the end of the item. In Topic 3, item 5 '*how important is it to ask the young person if they spend time with their family*' was modified to '*how important is it to ask the young person if they spend quality time with their family members*'. Altogether, the 23 remaining items for R3 consisted of six items from Topic 1; seven from Topic 2; five from Topic 3; two from Topic 4, and three from Topic 5.

6.4.4 R2 Section C Findings

The final section of the survey in R2 contained questions about the development and future use of the CAT-YC. Participants from both cohorts were asked to rank the five topics in order of preference from (1) '*most important'* to (5) '*least important'* for inclusion in the CAT-YC. As topics are ranked from (1) as the most important, the items ranked highest have the lowest mean average (Knighting et al. 2015, 2016). The standard deviation (SD) is included to show

the level of dispersion amongst participant responses. Table 26 below presents the findings for each cohort and the total sample.

Table 27: Ranking of Topics (Delphi)

Topic	Total Sample Ranking Mean (SD)	Professionals Ranking Mean (SD)	Young Carers Ranking Mean (SD)
Topic 1: Understanding the caring situation	**2nd** 2.79 (1.49)	**3rd** 2.97 (1.53)	**2nd** 2.36 (1.26)
Topic 2: Details of the care provided by the young person	**4th** 3.38 (1.24)	**4th** 3.20 (1.27)	**5th** 3.80 (1.05)
Topic 3: The young carer's health and social wellbeing	**1st** 1.86 (1.06)	**1st** 1.66 (0.86)	**1st** 2.32 (1.32)
Topic 4: The young carer's identity and self-esteem	**3rd** 3.00 (1.13)	**2nd** 2.95 (1.06)	**3rd** 3.12 (1.29)
Topic 5: Education and future plans	**5th** 3.98 (1.21)	**5th** 4.22 (0.98)	**4th** 3.40 (1.51)

Both of the cohorts ranked Topic 3 as the most important topic for inclusion in the CAT-YC. There was slight disagreement between the two cohorts as to whether Topic 1 or Topic 4 was the next most important topic, and again between the order of the bottom two topics, Topics 2 and 5. On closer analysis of the findings, several participants had commented on the difficulty they had ranking the topics, e.g. Professional (Prof) 04 found the ranking process '*almost impossible*'; Prof 25: '*very difficult*', and Prof 50: '*hard to rank as all are important*'. Similarly, one of the young carers (YC 05) reported that '*all are almost as important as each other but some are slightly more*', however they did not elaborate on this statement. The three most pertinent comments that needed consideration before designing the R3 survey came from Prof 23, who argued '*all are important - the ranking is a bit arbitrary';* Prof 44, who suggested that *'the importance of the 5 topics must be led by the young carer',* and Prof 15, who felt the importance of the topics was dependent on the age of the young carer, citing Topic 5 as being more important for those aged 16-18.

Participants were also asked to rate their views on the importance of assessing young carers for any needs arising from their caring role, using a Likert scale of (1) '*not at all important'* to (5) *'extremely important'*. Overwhelmingly, the majority of participants in both cohorts and the total sample rated the importance very highly, and none felt it was unimportant, as displayed in Table 28 below.

Table 28: Importance of Assessing the Needs of Young Carers

	Rating	Total Sample n (%)	Professionals n (%)	Young Carers n (%)
1	Not at all important	0 (0%)	0 (0%)	0 (0%)
2	Not very important	0 (0%)	0 (0%)	0 (0%)
3	Important	**5 (6%)**	0 (0%)	**5 (20%)**
4	Very important	**22 (26%)**	**10 (17%)**	**12 (48%)**
5	Extremely important	**57 (68%)**	**49 (83%)**	**8 (32%)**

*****As reported in Section 6.4, percentages have been rounded to the nearest whole number.

Recognising that caring situations can change over time, participants were asked how often they felt young carers' needs should be reviewed, as a minimum. Interestingly, there was a wide spread of opinion, with a percentage level four times higher in the young carer cohort than in the professional cohort expressing that young carers' needs should be reviewed monthly. The same percentage (28%) for both cohorts felt this should be every three months, and over 50% more professionals (64%) than young carers (40%) felt it should be either every six months, or annually. Table 29 below presents the full findings for this question.

Table 29: Frequency of Reviewing the Needs of Young Carers

	Frequency	Total Sample n (%)	Professionals n (%)	Young Carers n (%)
1	Monthly	13 (15%)	5 (8%)	8 (32%)
2	Every 3 months	24 (28%)	17 (28%)	7 (28%)
3	Every 6 months	28 (33%)	22 (37%)	6 (24%)
4	Annually	20 (24%)	16 (27%)	4 (16%)

The final question in Section C asked participants their views on which professional(s) should be responsible for using the CAT-YC. They were reminded that they could choose as many professionals as they wanted, but to remember that the person conducting the CAT-YC must be able to take action on any needs identified, whether that was personally, by making a referral, or by contacting an appropriate person or service. Table 30 below presents the findings for this question; percentages have not been totalled due to participants being able to select more than one option.

Table 30: Views on which Professionals should use the CAT-YC (Delphi)

	Professionals Occupations	Total Sample (n=85)		Professionals (n=60)		Young Carers (n=25)	
1	Carers' centre staff	61	**72%**	48	**80%**	13	**52%**
2	Social worker	60	**71%**	47	**78%**	13	**52%**
3	Teachers	60	**71%**	42	**70%**	18	**72%**
4	Anyone who has contact with young carers	48	**56%**	37	**62%**	11	**44%**
5	Other school staff	44	**52%**	33	**55%**	10	**40%**
6	G.P.	37	44%	30	50%	7	28%
7	Practice nurse	32	38%	29	48%	3	12%
8	School nurse	38	45%	32	53%	6	24%
9	Adult worker supporting the parent	38	45%	32	53%	6	24%
10	Other	10	12%	8	13%	2	8%

Interestingly, the top five professions selected by each cohort consisted of the same professions, namely: carers' centre staff; social workers, teachers, anyone who has contact with young carers, and other school staff. Similarly, the bottom four professions consisted of the same professions for each cohort: G.P., practice nurse, school nurse, and adult worker supporting the parent. It is perhaps not surprising that health care professionals were rated so low by the professional cohort, given the demographic occupations of the participants reported in Section A. Two comments were provided by young carers in the '*other*' category. One suggested online support services would be useful; the other felt a school counsellor could use the CAT-YC. Eight participants from the professional cohort made comments in the '*other*' category. One suggested having the possibility to self-refer, two felt youth workers

could use the CAT-YC, one suggested identified personnel in carers' charities and support groups, and one felt it should be used by someone who has a prior relationship with the young carer, so that they are more likely to be open and honest in their responses. The remaining three comments were observations rather than suggestions and not relevant to the findings. The following section sets out the process and findings from R3.

6.5 Delphi Survey Round Three

The main purpose of the survey for R3 was to try to gain consensus on the acceptance or rejection of the remaining 23 items from R2 that the two cohorts had disagreed on. The survey developed for R3 therefore comprised of two sections: A (demographics for any additional participants); and B (the 23 survey items for reconsideration). Controlled feedback was included in the design of the R3 survey, based on the group median score that each item was rated at previously (Keeney, Hasson and McKenna, 2011; Keeney, 2015). Items that had reached consensus in R2 did not form part of the survey for R3, but were displayed under each topic as a reminder of what had been previously accepted (Keeney, Hasson and McKenna, 2011).

6.5.1 Round Three Data Collection (Professionals and Young Carers 16-18)

The same 142 organisations who had been approached in R2 were contacted again by email in September 2018 and asked to circulate an invitation to take part in R3 to staff members and young carers aged 16-18. To try to enhance the response rate, the invitation contained information about how many people had participated in R2, together with a brief summary of R2 findings (Sandrey and Bulger, 2008) and a link to the R3 survey, which was created via SurveyMonkey®. The survey was again promoted on the social media site Twitter; therefore, it is not possible to know how many participants considered taking part or how many had previously taken part in R2, as the information collected was anonymous. However, analytics on SurveyMonkey® showed that the professional survey link was clicked on 77 times and the young carers aged 16-18 link was clicked on 18 times. The survey remained open for four weeks and data were collected from 74 professionals and 18 young carers aged 16-18, which equates to 97% of the total number who accessed it overall.

6.5.2 Round Three Data Collection (Young Carers 11-15)

As in R2, young carers aged 11-15 were not approached to take part in the online survey. Gatekeepers at the organisations who took part in R2 were contacted again to arrange a suitable time and place to facilitate small group meetings for R3. The same participants were invited to take part in R3 and data were collected at three meetings, which took place in Sept-Oct 2018 to coincide with the online survey. Due to the low overall ratings of items and lack of many open text comments by this cohort in R2, data were collected slightly differently for this round. Participants were given packs of laminated cards, each representing a number between 1-5. The items in the survey were read out, together with details of the previously accepted items and the same group feedback referred to in Section 6.5 earlier, and participants were asked to individually rate each item from (1) '*not at all important*' to (5) '*extremely important*' by selecting the card that matched their response. Once all responses to that item had been recorded, participants in the group were invited to discuss their reasons for rating it in the way they had and were given the opportunity to reconsider their score. This gave a greater insight into their responses and contrary to expectations, only two scores were changed as a consequence of the discussion, confirming the very individual nature of the young carers' responses. All comments were noted and added to each data set before being manually entered into SurveyMonkey® prior to analysis. The meetings took 60 minutes to facilitate and altogether, data were collected from 18 young carers aged 11-15.

6.5.3 Data Analysis Round Three

As in R2, data from the 11-15 year old participants were combined with those from the 16-18 year olds who took part online, and were analysed as one data set. Quantitative data from the survey were entered into IBM SPSS Statistics, Version 25 for analysis (Armonk, NY: IBM Corp, 2017). Data for Section A were analysed using descriptive statistics to describe the participants according to the demographic information gained. Data for Section B were analysed using measures of central tendency, frequency and levels of dispersion to provide results on the rating of items. Qualitative data from the open text comment boxes were thematically analysed, as in R2 and will be discussed later in this chapter.

6.6 Results and Findings Round Three

A total of 110 participants completed the R3 survey, comprising of 74 professionals and 36 young carers aged 11-18. This equates to 15% more participants than in R2, which is unusual in Delphi surveys (Donohoe and Needham, 2008). However, the higher participation rate may partly be due to R2 taking place in the summer and exam period (June/July), whereas R3 took place in the autumn (September/October). Furthermore, providing potential participants with a brief summary of the findings from R2 and details of how many participants had taken part in the earlier rounds, may have encouraged more participants to take part (Sandrey and Bulger, 2008). Results from Section A of the survey will be presented separately for each cohort, then the results of Section B will be presented together. Two participants from the young carer cohort chose not to include any demographic details, therefore statistics for Section A are based on 34 participants, but 36 for Section B.

6.6.1 R3 Section A Participant Profiles (Professionals)

The 74 professionals consisted of a range of staff working either directly or indirectly with young carers, in the paid and voluntary sectors. Findings were similar to those in R2, as many of the participants are likely to have been the same for both rounds. The biggest changes appeared to come from there being eight less participants in R3 from the North East, and ten more participants from Scotland than in R2. In the '*other*' category, one participant stated they were from the Republic of Ireland and another was from Canada. There were fewer young carers' support workers reported than in R3, however this may have been due to some participants choosing the additional category of young carers service manager, which was added following analysis of the comments in R2. The other main difference was in experience. Only 26% of participants reported working with young carers for nine or more years in this round, compared to 41% in R2. Table 31 on the following page displays all of the demographic characteristics of the professional participants.

Table 31: Demographic Profile of Professionals R3

Characteristics	n (%)	Characteristics	n (%)
Gender		**Region of Work**	
Male	12 (16%)	Greater London	3 (4%)
Female	61 (83%)	South East	8 (11%)
Prefer not to say	1 (1%)	South West	5 (7%)
		West Midlands	7 (10%)
Ethnicity		East Midlands	1 (1%)
White British	64 (87%)	North West	27 (37%)
White Other	6 (8%)	North East	2 (3%)
Black/Black British	1 (1%)	Yorkshire and the Humber	5 (7%)
Mixed/multiple ethnic groups	2 (3%)	East of England	1 (1%)
Prefer not to say	1 (1%)	Wales	1 (1%)
		Scotland	13 (18%)
		Other	2 (3%)
Length of Time in Role			
Less than 1 year	11 (15%)	**Job Title**	
1-2 years	11 (15%)	Young Carers Support Worker	32 (43%)
3-4 years	22 (30%)	Youth Worker	1 (1%)
5-6 years	8 (11%)	Social Worker	1 (1%)
7-8 years	3 (4%)	Learning Mentor/Pastoral Staff	2 (3%)
9 years or more	19 (26%)	Teaching Assistant	3 (4%)
		Young Carers Service Manager	11 (15%)
		Volunteer	1 (1%)
		Psychologist/Psychotherapist	3 (4%)
		Other	20 (27%)

6.6.2 R3 Section A Participant Profiles (Young Carers)

In R3, despite more participants in the 16-18 year old category taking part than in R2, the average age only rose from 14.4 to 14.7 and they comprised of 26 girls and eight boys. The majority of participants (72%) were from the towns and cities in North West England where the small group meetings took place. The remaining participants were from the 16-18 year old category, who took part online. Most of the participants primarily cared for their mother (20), five for their father, six for a sibling and three for a grandparent. The main reasons for their family member needing care were due to a mental health condition (41%), a physical

health condition (32%) or a physical disability (32%). As in R2, some participants selected more than one reason, therefore the percentages shown for that category in Table 32 below are only an indication of the prevalence of affecting health conditions.

Table 32: Demographic Profile of Young Carers R3

Characteristics	n (%)	Characteristics	n (%)
Gender		**Town/City/Area**	
Male	8 (24%)	Liverpool	6 (19%)
Female	26 (76%)	Sefton	8 (25%)
Age		Wigan	9 (28%)
11	4 (12%)	Scotland	3 (9%)
12	4 (12%)	Staffs	2 (6%)
13	4 (12%)	Yorkshire	1 (3%)
14	5 (15%)	Manchester	1 (3%)
15	1 (3%)	West Midlands	1 (3%)
16	5 (15%)	Kent	1 (3%)
17	8 (24%)	(**2 participants did not state a location)*	
18	3 (9%)		
Ethnicity		**Main Care Recipient**	
White British	26 (76%)	Mother	20 (59%)
White Other	1 (3%)	Father	5 (15%)
Asian/Asian British	3 (9%)	Older Sibling	3 (9%)
Mixed/multiple ethnic group	2 (6%)	Younger Sibling	3 (9%)
Don't Know	2 (6%)	Grandparent	3 (9%)
Length of Time in Caring Role		**Reason for Recipient Needing Care**	
1-2 years	9 (26%)	Physical Health Condition	11 (32%)
3-4 years	14 (41%)	Physical Disability	11 (32%)
5-6 years	5 (15%)	Mental Health Condition	14 (41%)
7-8 years	2 (6%)	Sight or Hearing Loss	4 (12%)
9 years or more	4 (12%)	Learning Difficulty	6 (18%)
Hours Spent Caring Each Week		Drug/Alcohol Dependency	2 (6%)
Less than 10	7 (21%)	Prefer not to say	2 (3%)
10-20	11 (32%)	(**Some participants selected more than one reason for care*)	
21-30	11 (32%)		
31-40	0 (0%)		
41 or more	5 (15%)		

6.6.3 R3 Section B Findings

The same method of analysis used in R2 was replicated for this round to identify items which met the criteria. Descriptive statistics were used to explore the median and interquartile range (IQR) of the ratings of both young carer and professional cohorts and for the total sample, for each of the remaining 23 items within the five topics (Knighting et al. 2015, 2016). As discussed in section 6.4.3, the criterion to accept an item in the Delphi survey was set for at least 60% of participants in both the young carer and professional cohorts rating an item as equal to or greater than a median level of (4) '*very important*' on a five-point Likert scale. Accepted items from this round were removed and added to the previously accepted items from R2 for further consideration; this process is discussed later in this section. The criterion for rejecting an item was set at less than 60% of participants from both cohorts rating an item as equal to or greater than a median level of (4). Those items where there was disagreement between the cohorts, i.e. 60% or more participants from one cohort but not the other rating an item at a median level of (4) or higher, were also rejected, as consensus had not been achieved after both rounds.

The results from each cohort were tabulated separately and then combined into a larger table to show the number of participants, median and IQR, and percentage consensus levels for each of the 23 items within their topics. Table 33 on the following page shows an example of how data findings were tabulated for one of the topics; the full table of results for all of the items and topics in this round are in Table 34, Appendix 13.

Table 33: Example from R3 Findings (Total Sample; Topic 3)

	TOPIC 3: THE YOUNG CARERS OWN HEALTH AND WELLBEING How important is it to ask the young person...	Total Sample (N)	Total Sample Median (IQR)	Total Sample Consensus [N (%)]	Profs (N)	Profs Median (IQR)	Profs Consensus [N (%)]	Young Carers (N)	Young Carers Median (IQR)	Young Carers Consensus [N (%)]	Criteria*
1	...if they need support with their physical health?	108	4 (1.00)	89 **(82%)**	73	4 (1.00)	58 **(82%)**	35	4 (1.00)	29 **(83%)**	MET
3	...if they have a friend or family member they can speak to or contact for help or support?	108	5 (1.00)	93 **(86%)**	73	5 (1.00)	66 **(91%)**	35	4 (2.00)	27 **(77%)**	MET
5	...if they spend time with their family members?	106	4 (2.00)	73 69%	71	4 (1.00)	57 (80%)	35	3 (1.00)	16 (46%)	REMOVE
7	...if they attend/receive support from a young carers' service?	108	4 (2.00)	75 **(70%)**	73	4 (2.00)	53 **(73%)**	35	4 (2.00)	22 **(63%)**	MET
8	...if they need help accessing a group, or any other clubs in their schools or local community?	107	4 (1.00)	82 **(77%)**	73	4 (1.00)	58 **(82%)**	34	4 (1.00)	22 **(65%)**	MET

**** If 60% met note MET, if disagreed note RE-RATE, if 60% not met note REMOVE***

Criterion to accept an item: at least 60% of both the young carer and professional cohorts rated an item as (4) 'important' or (5) 'extremely important'.

Criterion for rejecting an item: any items that did not meet the 60% criteria in both cohorts.

As in R2, only one item out of the 23 did not meet the 60% consensus criterion by both cohorts and was therefore immediately rejected. There was a consistently high mean level (80%) of consensus for rating the remaining 22 items at a median level of (4) or higher by the professional cohort again, which was only one percent lower than in R2. Similarly to R2, the consensus level in R3 was lower by the young carer cohort at a mean level of 62% for the remaining items, but this level was significantly higher than in R2 (54%). This may have partly been due to the survey containing fewer items for consideration, or that participants who had taken part in the earlier round were familiar with the items and had therefore had the opportunity to consider them fully previously. There was still disagreement between the cohorts about nine items, therefore they were rejected in accordance with the consensus criteria. In this round of the survey, 13 items reached the criterion to accept an item, making a total of 26 items altogether when added to the 13 accepted items from R2.

The 26 items consisted of six items from Topic 1 (Understanding the Caring Situation); five items from Topic 2 (Details of the Care Provided by the Young Person); seven items from Topic 3 (The Young Carers Own Health and Social Wellbeing); three items from Topic 4 (The Young Carers Identity and Self-Esteem), and five items from Topic 5 (Education and Future Plans). Although median scores were used to determine consensus of items in R2 and R3, for the purposes of reducing the items further, the mean level of each item achieving 60% or more consensus from both cohorts rating an item a (4) or (5) in either R2 or R3 was calculated and used to priority rank the statements from most important to least important, as recommended by Hasson, Keeney and McKenna (2011). A full table of the 26 items, ranked by mean and containing relevant descriptive statistics, is presented in Table 35 on the next page. The topics and items within the topics are numbered to reflect their original position in the first survey (R2) of 37 items.

Table 35: 26 Items Reaching Consensus in R2 & R3, Ranked by Mean

Topic (Item No)	Items Reaching Consensus How important is it to ask the young person...	Consensus Level	Total Sample Mean (SD)	Rank
1 (9)	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	91%	4.56 (0.69)	**1**
3 (2)	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?	90%	4.54 (0.78)	**2**
1 (4)	...if they need support to continue their caring role?	89%	4.51 (0.75)	**3=**
2 (9)	...if they are undertaking tasks they don't want to do?	84%	4.51 (0.77)	**3=**
2 (6)	...if they are giving medication to the person they care for, or checking it has been taken?	88%	4.49 (0.81)	**5**
5 (4)	...if there is anything that could help reduce stress/anxiety at or about school/college?	94%	4.43 (0.74)	**6**
4 (3)	...if they feel bullied or stigmatised by others for their caring role?	87%	4.36 (0.85)	**7=**
3 (3)	...if they have a friend or family member they can speak to or contact for help or support?	86%	4.36 (0.85)	**7=**
1 (3)	...if they have support from another adult in the home?	84%	4.34 (0.75)	**9**
3 (6)	...if they want a break or time away from their caring role?	83%	4.30 (0.85)	**10**
4 (4)	...if they want or need support speaking to people about their caring role?	82%	4.28 (0.86)	**11**
3 (4)	...if they spend time with their friends?	82%	4.24 (0.86)	**12**
2 (1)	...about the type of things they do to help in their caring role?	81%	4.21 (0.87)	**13**
3 (1)	...if they need support with their physical health?	82%	4.20 (0.81)	**14**
5 (2)	...if they want or need help to make staff at school/college aware of their caring role?	82%	4.19 (0.98)	**15**
2 (8)	...if they are looking after siblings (due to a parent's poor health*)? (* extra words added between rounds, following feedback)	84%	4.18 (0.94)	**16**
1 (6)	...if they need support with financial matters, e.g. benefits, housing?	72%	4.11 (1.01)	**17**
1 (8)	...if they feel included in support decisions about their family member?	77%	4.10 (0.89)	**18=**
2 (2)	...if they are providing emotional support, e.g. keeping company or comforting?	75%	4.10 (0.91)	**18=**
4 (5)	...if they have someone who can speak on their behalf, if necessary?	74%	4.10 (0.97)	**18=**
5 (5)	...if they need additional advice/support about future education or career options?	78%	4.06 (0.93)	**21**
5 (3)	...if there are specific needs they have in school/college, e.g. extra time for homework?	80%	4.05 (0.87)	**22**
3 (8)	...if they need help accessing a group, or any other clubs in their schools or local community?	77%	4.02 (1.01)	**23**
3 (7)	...if they attend/receive support from a young carers' service?	70%	3.90 (1.01)	**24**
5 (1)	...if there is a named staff member at their school/college for young carers?	67%	3.89 (1.08)	**25**
1 (2)	...how much time they spend on average caring each day/week?	65%	3.83 (1.08)	**26**

The following section contains findings from thematic analysis of the open text comments provided by participants in R2 and R3 of the survey, before discussing the aim, process, results and findings of an expert panel in reviewing and finalising the top ranked items for inclusion in the CAT-YC.

6.7 Qualitative Data Findings

Findings from the open text comment boxes by both cohorts in R2 and R3 were thematically analysed, as in phase one of the study. Data were coded and collated into themes, then reviewed across the data set from both cohorts to ensure coherence (Braun and Clarke, 2006, 2013). In R2, 52 comments were made by 26 professionals and fourteen comments were made by eight young carers about the items, topics or the survey in general. In R3, 47 comments were made by seventeen professionals and 34 comments were made by fifteen young carers. Although the comments related to the overall development of the CAT-YC, three overlapping themes were identified in the data: Choice and Voice; Safeguarding and Risk; and Screening versus Assessment. As the surveys were anonymous, identification numbers were assigned to each participant during analysis. Verbatim quotes from the participants will be used to illustrate the findings and will be labelled according to whether they were made by a professional (Prof) or young carer (YC), and the round (R) they were made in; e.g. Prof 01-R2, YC 01-R3.

6.7.1 Choice and Voice

This theme was developed from comments made by participants from both cohorts about the importance of using the CAT-YC to encourage young carers to talk about their caring role and be aware of their choices. For professionals, the emphasis was on ensuring young carers did not feel obligated to provide care:

> '*Caring should be a choice, not a requirement [...] ask what would help minimise the impact*' Prof 17-R2

> '*It's important that questions are framed not to encourage the caring role or make the person feel obligated to continue in their caring role*' Prof 26-R2

> '*They have a right not to care, regardless of age*' Prof 04-R3

Furthermore, several comments were made by professionals highlighting the often gradual increase in caring tasks that some young carers may experience. As previously reported in the literature, caring can develop insidiously over time and the cumulative effects may not be apparent until discussed, making it imperative that the right questions are asked at the screening stage to ascertain the level of any potential impact:

> '*It's important not to perpetuate young carers taking on responsibilities and continuing to be carers more and more*' Prof 24-R2

> '*Caring is a choice and while the young carer may not have had a choice in caring as a child, it is essential they recognise their choice as they mature. It is our role to ensure they are aware they have a choice and support to accommodate the right balance for them in this*' Prof 05-R2

However, although many professionals spoke about choice, they also cautioned against making unrealistic promises about the availability of support, highlighting the increasing lack of resources and importance of knowing what is available locally:

> *'Depending on area, access to counselling and support is very limited'* Prof 16-R2

> '*Unfortunately, many young carer organisations are unable to offer much respite'* Prof 09-R2

This is an important factor when considering the 'next steps' section of the CAT-YC for any items in the final tool that require local knowledge and expertise. For some young carers, understanding or even realising they have a choice was less apparent and they spoke more about wanting the opportunity to discuss their caring situations. The focus of this appeared to be linked to the practicalities of supporting them in their caring role:

> '*Once you understand what a person is going through, you can help them*' YC 07-R2

'*This [asking how they feel] is important because a carer may be pushed out of their comfort zone*' YC 08-R2

'*Sometimes I don't need support because I'm old enough to do it. But I would like training, so I can put my mum in the right position and lift her*' YC 03-R3

For several young carers, having the option to choose which member of staff at school they felt comfortable speaking to about their caring role, and who the information could be shared with, was an important factor that may also need further consideration when developing the 'next steps' section of the CAT-YC:

'*It has to be on a young carer's own terms whether they want teachers to tell anyone else or no*t' YC 15-R3

'*There is someone for young carers at my school, but I don't like her, so I'd rather go to my head of year*' YC 08-R3

Again, having the ability to exercise choice in school was something that some young carers may have felt lacking in other areas of their lives. Several young carers reported the importance to them of going to appointments with the family member they cared for. This appeared to be due to concerns about not being given as much information as they would like:

'*It's really important to go to appointments so that a parent doesn't lie to you about what the doctor said*' YC 06-R3

'*I want to go to appointments, so I know what's happening to them'* YC 08-R3

'*Carers need to be aware of needs and health plans'* YC 05-R2

Of course, this must be balanced with issues surrounding confidentiality and may be more relevant to discuss during a full assessment, rather than screening. As one professional pointed out, '*want*' and '*need*' have separate meanings and the cared for has a right to confidentiality and to be safeguarded. Moreover, even where there is agreement to share information between all significant parties, there may be an impact from missing school due

to attending appointments that would need to be considered. Further considerations relating to the impact of caring, together with risks to the young carer and their family members' health and wellbeing were apparent in the next theme.

6.7.2 Safeguarding and Risk

This was a theme that revealed potential dangers to both young carers and the people they cared for. This might also extend to younger siblings being at risk, particularly if medication is not stored safely, or they are left unattended. Resource issues were raised again, with one professional recognising that:

> '*We don't live in an ideal world and making their caring responsibilities as safe for them and the person they are looking after is probably the best we can do*' Prof 14-R3

From a practical aspect, young carers could be at risk of injuring themselves or others, or making medical errors whilst providing care, and several professionals gave examples of concerns they had about safety and wellbeing:

> '*Risks of them taking [medication] or overdosing the cared for*' Prof 10-R2

> '*Are they at risk of an injury because of lifting? Are they upset providing personal care to a parent?*' Prof 17-R3

> '*Are they being abused (physically, emotionally, sexually, financially)?*' Prof 11-R2

This was a concern that some young carers also recognised, although their focus was more on potential risks to their family member's physical health, rather than whether, or if, they might be at risk of harm themselves:

> '*Because if you give the wrong medicine it could kill them*' YC 11-R3

> '*They need to be asked what they do, in case they do something wrong*' YC 13-R3

Some comments for consideration related to closed family systems or cultural differences that may discourage young carers from getting support, even when needed. Several young carers felt that '*all kids should do some chores',* suggesting there is a fine line between what may be perceived as normal and age appropriate, and what may be regarded as excessive and/or inappropriate. This is ultimately down to the judgment of the professional conducting the screening, and flexibility around adapting items or action points in the CAT-YC may be required by them. Young carers themselves commented about how changes in family dynamics or their caring role could potentially put them at risk:

> *'People need to be made aware if it [caring role] changes, or they are pushing themselves too much*' YC 05-R2

> '*Family circumstances are important, e.g. if there has been a divorce, who is in the home etc*' YC 09-R2

This highlights the importance of regular reviews and ongoing monitoring, which will be a consideration for individual organisations to decide, and must be based on their own procedures. This was confirmed by one of the professionals, who stated that:

> '*Outside of a formal review, young carers need to be continually assessed as their caring role/impact can change daily/weekly/monthly, given the nature of some of the parents illnesses'* Prof 17-R2

One of the design features of the CAT-YC is to include space for professionals to agree when reviews should take place, and who is responsible for initiating and following up any action points from the 'next steps' section. It may be that a question regarding safeguarding, or child protection concerns will need to be included in the demographic details section of the CAT-YC, rather than as an item in the main body of questions. As one professional reported, their first query when meeting a young carer for the first time is:

> '*Is this a crisis intervention?*' Prof 24-R2

This will be discussed further in the consultation stage of phase three and reported on in the next chapter. The final theme identified in the comments relates to the content and wording

of the items, and whether they were considered more appropriate for a screening or assessment tool.

6.7.3 Screening versus Assessment

Most of the professionals reported the importance of ensuring the questions in the CAT-YC are open, to encourage young carers to talk about their caring role. One professional suggested this may also help the young carer explore their feelings of responsibility related to their caring role, to help understand the potential level of impact:

> '*E.g. they may go on to say they like to give their mum medication, but the feelings behind this might be that it's so they know their mum will stay alive, rather than actually preferring this task to housework'* Prof 32-R2

> *'Open questions are better, in my opinion'* Prof 12-R3

However, some young carers were clear that they did not like being asked about their caring role or family situation, which suggested in-depth questions may be more suitable for a full assessment when hopefully a relationship has been established, rather than at a screening stage:

> *'Don't ask too much personal information'* YC 05-R2

> '*I don't like teachers knowing'* YC 13-R3

> '*I don't like it when I'm asked about what I do – it's nobody else's business' YC* 03-R3

There were several comments made by professionals about the relevance, or irrelevance of asking some of the items at screening stage:

> *'[Support with physical health] is very important at screening stage [...] it references sleep (or lack of it), healthy eating (or lack of it), and a range of issues which might negatively impact attendance at school or social activity'* Prof 17-R3

'At screening stage, it is enough to know that a young person is caring at this point in time, and that they are not supported or engaged with support planning' Prof 08-R3

'*Asking about undertaking tasks they do not want to do is irrelevant at screening stage*' Prof 16-R3

Several comments were also made by professionals about whether some of the items were more appropriate for assessment than screening:

'*Questions [about whether they need support] are more important at assessment stage, because this information is what informs the support plan*' Prof 14-R3

'*If targeted advocacy is needed, this will become apparent at assessment stage'* Prof 15-R3

There was some disagreement between professionals as to who should carry out the screening. One professional reported that most of the young carers at their organisation would prefer to speak to a health professional than an identified member of staff at school. However, very few health care professionals completed the Delphi survey, despite being actively targeted, suggesting less awareness by them of young carers and their needs. Conversely, one professional felt that school staff were best equipped to use the CAT-YC, as they had the advantage of regular and prolonged contact with the young carer. Another professional stated it was better for a young carer's support worker to carry out the screening, and felt it was important not to ask too many questions about staff at school:

'*So long as we know what the school is, we don't need to ask who the named staff member is at this stage; we will work this out ourselves, and it's not relevant to a screening tool'* Prof 16-R3

Several professionals raised the point that screening questions for 16-18 year olds needed to focus on life beyond compulsory education, and whether young carers wanted to continue caregiving, to ensure they had relevant support in negotiating their future plans:

'Extremely important [asking about continuing to care] as there are few roles where this would be asked, and it is presumed far too often. The young carer may also need support addressing this with the family' Prof 02-R3

'Transitional ages of 16-18 are the most essential time to ensure young adult carers feel able to move away from their caring role, if they wish, or to balance it with their own aspirations' Prof 23-R2

'I believe the most influential times are 16-18 and it is essential young carers are captured at the beginning of this' Prof 14-R2

These observations may lead to an additional optional item in the CAT-YC, specifically for 16-18 year olds, and will be considered further in the consultation stage of phase three. However, in order to reduce the accepted items from the findings of the Delphi survey rounds to ten items for inclusion in the pilot version of the CAT-YC, as referred to in Chapter Two, a virtual expert panel was convened for a fourth round to refine and reduce the items further. The next section explains the aim and role of the expert panel, and the process of recruitment, data collection and analysis of the findings from this fourth round.

6.8 Role of the Expert Panel

The aim was to convene a virtual panel of individuals, from national and regional organisations that have a strategic role in young carer support, and young carers who had participated in earlier phases. Their purpose was to comment on the list of top ranked items from the Delphi survey findings, and choose and rank a final list of ten items for the pilot CAT-YC. The rationale for having ten items was based on the pragmatic need to not overburden young carers or professionals working with them by having too many questions in the CAT-YC. In the development of the original CAT, the top two ranked items in each of that study's eight topics were reviewed and ranked by an expert panel (Knighting et al. 2015, 2016). However, if the same strategy was applied to this study, five items from Topics 1, 2 and 3 would be excluded, despite them scoring a higher mean average than the second of the top two ranked items in Topic 5. Therefore, a pragmatic decision was taken to employ a different strategy to reduce the number of items sent to the expert panel, as explained overleaf.

From the 26 accepted items, the ten items ranked highest by mean by both cohorts overall were selected for consideration by the expert panel, as displayed in blue in Table 36 on the following page. As more professionals participated in the Delphi rounds than young carers, the top ten items from each cohort, shaded yellow and green respectively, are also included in the table for information, to demonstrate that equal consideration was given to hearing the voices of both groups. Eight items for the professionals and eight items for the young carers were already in the overall top ten. The remaining two items in the top ten for each cohort were added to the top ten overall, resulting in 14 items for inclusion. Two more items (ranked 11th and 13th overall) were added to the table for consideration, despite not being ranked in the top ten by either or both cohorts. The first of these was added to provide more balance to the representation of the topics, as Topic 4 was ranked the second most important topic by the professional cohort participants in the Delphi survey. The second item was added due to several comments in the qualitative data from R2 and R3 suggesting it was a useful screening item, particularly if trying to start a conversation or identify whether the young person has a caring role.

This resulted in 16 items for the expert panel to individually review, comment on, and choose and rank their top ten items from, as displayed in Table 36 on the next page. The 16 items were listed in a three-section survey created through SurveyMonkey®, with separate demographic sections for each cohort. The first section asked participants to review the list of items and topics and provide feedback. The second section asked participants to choose and rank their top ten items; the final section asked who should use the CAT-YC and how often, and for demographic details to be provided.

Table 36: 16 Items sent to the Expert Panel for Review and Ranking

Topic (Item No)	Top Items ranked by overall Mean: How important is it to ask the young person...	Delphi Round	Total Sample Consensus Level [N (%)]	Total Sample Mean (SD)	Profs Mean (SD)	Young Carers Mean (SD)
1 (9)	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	R2	95 (91%)	**4.56 (**0.69)	**4.69** (0.50)	**4.23** (0.97)
3 (2)	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?	R2	93 (90%)	**4.54 (**0.78)	**4.74** (0.55)	**4.00** (1.02)
1 (4)	...if they need support to continue their caring role?	R3	109 (89%)	**4.51 (**0.75)	**4.68** (0.59)	**4.16** (0.93)
2 (9)	...if they are undertaking tasks they don't want to do?	R3	108 (84%)	**4.51 (**0.77)	**4.68** (0.67)	**4.16** (0.90)
2 (6)	...if they are giving medication to the person they care for, or checking it has been taken?	R2	94 (88%)	**4.49 (**0.81)	**4.69** (0.63)	3.95 (0.99)
5 (4)	...if there is anything that could help reduce stress/anxiety at or about school/college?	R2	90 (94%)	**4.43** (0.74)	**4.53** (0.60)	**4.14** (0.99)
3 (3)	...if they have a friend or family member they can speak to or contact for help or support?	R2	93 (86%)	**4.36 (**0.85)	**4.50** (0.78)	**4.06** (0.93)
4 (3)	...if they feel bullied or stigmatised by others for their caring role?	R2	90 (87%)	**4.36 (**0.85)	4.41 (0.70)	**4.23** (1.11)
1 (3)	...if they have support from another adult in the home?	R2	96 (84%)	**4.34** (0.75)	**4.52** (0.63)	3.86 (1.03)
3 (6)	...if they want a break or time away from their caring role?	R2	92 (83%)	**4.30** (0.85)	4.40 (0.75)	**4.06** (1.02)
2 (2)	...if they are providing emotional support, e.g. keeping company or comforting?	R2	94 (75%)	4.10 (0.91)	**4.74** (0.55)	3.82 (1.13)
3 (4)	...if they spend time with their friends?	R2	93 (82%)	4.24 **(**0.86)	**4.45** (0.70)	3.68 (1.04)
3 (1)	...if they need support with their physical health?	R3	108 (82%)	4.20 **(**0.81)	4.25 (0.78)	**4.10** (0.87)
5 (2)	...if they want or need help to make staff at school/college aware of their caring role?	R3	107 (82%)	4.19 **(**0.98)	4.27 (0.88)	**4.03** (1.17)
4 (4)	...if they want or need support speaking to people about their caring role?	R2	90 (82%)	4.28 (0.86)	4.43 (0.70)	3.86 (1.08)
2 (1)	...about the type of things they do to help in their caring role?	R3	108 (81%)	4.21 (0.87)	4.38 (0.77)	3.87 (.96)

Topic 1: Understanding the caring situation
Topic 2: Details of the care provided by the young person
Topic 3: The young carer's health and social well-being
Topic 4: The young carer's identity and self-esteem
Topic 5: Education and future plans

6.8.1 Recruitment and Demographics of the Expert Panel

The original aim was to recruit approximately ten members to be part of the virtual panel, consisting of equal numbers of professional and young carer participants. However, due to the reported difficulties in recruiting members to participate in an expert panel, oversampling was used as a strategy to counteract this (Goodman and Evans, 2015). Nineteen professionals from national and regional organisations that have a strategic role in young carer support were approached by invitation in December 2018 to be part of the virtual panel. Although eleven had agreed to take part, eight participated by completing the online survey in January 2019. Demographic details of the professionals who took part are displayed in Table 37 below.

Table 37: Demographic Profile of Professionals (Expert Panel)

Characteristics	n (%)	Characteristics	n (%)
Gender		**Region of Work**	
Male	2 (25%)	South East	3 (38%)
Female	6 (75%)	South West	1 (13%)
		West Midlands	1 (13%)
Job Title		North East	1 (13%)
Development Manager (Young Carers Service)	1 (13%)	East of England	1 (13%)
NHS Partnership Manager for Young Carers	1 (13%)	Wales	1 (13%)
Operations Manager (Young Carer Service)	1 (13%)		
Regional Manager of Children's Charity supporting Young Carers	1 (13%)	**Length of Time in Role**	
		1-2 years	1 (13%)
Senior Research & Policy Officer for organisation supporting Young Carers	1 (13%)	3-4 years	2 (25%)
		5-6 years	1(13%)
Manager of Young Carers Service	3 (38%)	9 years or more	4 (50%)

Additionally, gatekeepers at the organisations who took part in earlier phases of the study were approached and asked to invite up to five young carers aged 16-18 each, who they felt would like to be part of the expert panel. The rationale for only including young carers aged 16-18 was based on the panel being conducted virtually, and as reported in Chapter Four, young carers aged 11-15 were not approached or encouraged to take part in the study online

(UK Council for Child Internet Safety, 2016). Again, oversampling was used as a strategy to counteract a potentially low response rate, however thirteen participants agreed to take part and eleven completed the online survey, to coincide with participation by the professionals. Demographic details of the young carers who took part are displayed in Table 38 below.

Table 38: Demographic Profile of Young Carers (Expert Panel)

Characteristics	n (%)	Characteristics	n (%)
Gender		**Town/City/Area**	
Male	3 (27%)	Liverpool	4 (36%)
Female	8 (73%)	Sefton	1 (9%)
		Wigan	6 (55%)
Age			
16	2 (18%)	**Main Care Recipient**	
17	6 (55%)	Mother	10 (91%)
18	3 (27%)	Father	1 (9%)
Length of Time in Caring Role		**Reason for Recipient Needing Care**	
1-2 years	1 (9%)	Physical Health Condition	6 (55%)
3-4 years	3 (27%)	Physical Disability	3 (27%)
5-6 years	3 (27%)	Mental Health Condition	5 (45%)
7-8 years	1 (9%)	Sight or Hearing Loss	3 (27%)
9 years or more	3 (27%)	Drug/Alcohol Dependency	1 (9%)
		Prefer not to say	1 (9%)
		(**Some participants selected more than one reason for care*)	

6.8.2 Frequency of Reviews

Participants in the expert panel were asked their views of how often the needs of young carers should be reviewed, as a minimum. '*Every six months*' was the option most frequently selected by participants from both cohorts, with almost half of the participants overall choosing this option. Five participants selected the '*other*' category: one young carer felt needs should be reviewed bi-weekly; two professionals and one young carer felt reviews should be based on individual circumstances; and one young carer suggested it should be

decided by the person using the CAT-YC with the young carer. Table 39 below displays the findings from this question.

Table 39: Frequency of Reviewing the Needs of Young Carers (Expert Panel)

	Frequency	Total Sample n (%)	Professionals n (%)	Young Carers n (%)
1	Monthly	1 (5%)	0 (0%)	1 (9%)
2	Every 3 months	2 (11%)	1 (13%)	1 (9%)
3	Every 6 months	9 (47%)	3 (38%)	6 (55%)
4	Annually	2 (11%)	2 (25%)	0 (0%)
5	Other	5 (26%)	2 (25%)	3 (27%)

6.8.3 Views on which professionals should use the CAT-YC

Participants in the expert panel were asked who they felt should be responsible for using the CAT-YC. As in the Delphi survey, participants could choose more than one option, therefore the findings in Table 40 below have not been totalled due to participants being able to select more than one option.

Table 40: Views on which Professionals should use the CAT-YC (Expert Panel)

	Professionals Occupations	Total Sample n (%)	Professionals n (%)	Young Carers n (%)
1	Carers' centre staff	10 (53%)	5 (63%)	5 (45%)
2	Social worker	13 (68%)	6 (75%)	7 (64%)
3	Teachers	9 (47%)	5 (63%)	4 36%)
4	Anyone who has contact with young carers	10 (53%)	5 (63%)	5 (45%)
5	Other school staff	11 (58%)	5 (63%)	6 (55%)
6	G.P.	11 (58%)	6 (75%)	5 (45%)
7	Practice nurse	5 (26%)	4 (50%)	1 (9%)
8	School nurse	11 (58%)	6 (75%)	5 (45%)
9	Adult worker supporting the parent	13 (68%)	7 (88%)	6 (55%)
10	Other	3 (16%)	2 (25%)	1 (9%)

For professionals, the option selected most frequently was '*adult worker supporting the parent*', whereas for young carers the most selected option was, perhaps surprisingly, '*social worker'*. Three participants also left comments in the '*other*' category: one young carer suggested a counsellor; one professional suggested Children's Early Help Services; and one professional wondered whether the CAT-YC could be used as a self-reporting tool.

6.8.4 Review of Items and Ranking of Topics by the Expert Panel

The expert panel were asked to comment on the 16 items within their five topics, and then to rank the topics according to priority. Seven of the professionals provided comprehensive comments, however only five young carers left feedback, which was very brief. Thematic analysis of the comments identified two themes: '*what's missing?'*; and '*reframing and semantics*'. These will be considered before discussing the ranking of topics.

6.8.4.1 What's Missing?

Although several comments were made referring to the importance and comprehensiveness of the items, e.g.

> '*Very comprehensive [...]appears holistic and should be suitable for all professionals to use'* Prof-06
>
> *'I felt like all the items should definitely be included'* YC-04

there were also a number of comments, particularly by the professionals, that referred to items they felt were missing. Most of these comments related to items previously rejected in the earlier Delphi survey rounds, such as questions about time spent caring, providing personal care, peer support, or wanting more information about the family member's medical condition. However, three new points were raised:

> *'Is the adult being supported by other professionals?'* Prof-05
>
> '*Nowhere are we asking about financial pressures'* Prof-06
>
> '*Ask about their own mental health as a result of caring'* YC-08

The first of these points could potentially be included in the demographic details section of the CAT-YC, as part of establishing whether other agencies or professionals are involved with the family, and this will be raised in the consultation stage of phase three. The second point may be something that is more relevant at assessment stage than screening. The last point is likely to be covered by the second item (*...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?*) on the list of 16 items in Table 34.

6.8.4.2 Reframing and Semantics

A number of comments were made about the wording of some of the items in the list, with suggestions about how to improve them:

> '*Number 4 (...if they are undertaking tasks they don't want to do?) *prefer not to do* sounds nicer'* YC-11

> '*In a screening tool the word 'caring' may not be understood by the young person. Many will regard what they do as just 'ordinary life in our family' rather than caring for someone. They may need an explanation of what is meant by the word 'caring'* Prof-07.

Similarly, there were several comments suggesting that some items could be reframed to make them clearer or more user friendly. One professional felt that by asking young carers '*if they need support with...*' there was a possibility they might answer '*no*'. They suggested it might be more useful to ask open questions such as:

> '*How does being responsible for looking after someone make you feel?'* Prof-07

Moreover, one young carer raised a salient point that:

> '*Most young carers don't know what support is available to them'* YC-11

Another professional suggested changing one of the items in Topic 5:

'Topic 5 - 1st question assumes there is stress/anxiety at or about school/college. Suggest re-framing the question to say: 'is there any specific help/support you need in relation to school/college' Prof-05.

6.8.4.3 Ranking of Topics

Young carers in the expert panel ranked the topics in a similar order to those in the Delphi survey, with Topic 3 as the '*most important*' and Topic 2 as the '*least important'*. However, professionals ranked the topics differently to both the young carers, and to how they had been ranked by professionals previously. As before, several comments alluded to the difficulty some participants had ranking the topics:

'Almost impossible to rank' Prof-07

'Topics 1 and 2 are quite similar' YC-03

'*All are equally important. Understanding the caring situation and the care being provided will help establish the impacts that this is having on the young carers health and well-being and their ability to think about the future*' Prof-01

Table 41 on the next page shows the positions as ranked by each cohort and the total sample, both from the Delphi survey and from the expert panel respectively.

Table 41: Ranking of Topics and Comparison

Topic	Delphi Total Sample Ranking Mean (SD)	Expert Panel Total Sample Ranking Mean (SD)	Delphi Profs Ranking Mean (SD)	Expert Panel Profs Ranking Mean (SD)	Delphi Young Carers Ranking Mean (SD)	Expert Panel Young Carers Ranking Mean (SD)
Topic 1: Understanding the caring situation	**2nd** 2.79 (1.49)	**2nd** 2.68 (1.20)	**3rd** 2.97 (1.53)	**3rd** 2.38 (1.30)	**2nd** 2.36 (1.26)	**3rd** 2.91 (1.34)
Topic 2: Details of the care provided by the young person	**4th** 3.38 (1.24)	**3rd** 2.95 (1.78)	**4th** 3.20 (1.27)	**1st** 2.00 (1.31)	**5th** 3.80 (1.05)	**5th** 3.64 (1.80)
Topic 3: The young carer's health and social wellbeing	**1st** 1.86 (1.06)	**1st** 1.84 (0.83)	**1st** 1.66 (0.86)	**2nd** 2.25 (0.89)	**1st** 2.32 (1.32)	**1st** 1.55 (0.69)
Topic 4: The young carer's identity and self-esteem	**3rd** 3.00 (1.13)	**5th** 3.89 (0.94)	**2nd** 2.95 (1.06)	**5th** 4.25 (0.71)	**3rd** 3.12 (1.29)	**4th** 3.45 (1.13)
Topic 5: Education and future plans	**5th** 3.98 (1.21)	**4th** 3.74 (1.19)	**5th** 4.22 (0.98)	**4th** 4.13 (1.13)	**4th** 3.40 (1.51)	**2nd** 3.45 (1.21)

6.8.5 Choosing the Top Ten (Expert Panel)

After commenting on each of the 16 items and ranking the five topics, the expert panel were asked to individually rank the 16 items in the survey from (1) '*highest priority*' to (10) '*least highest priority*', for inclusion in the pilot CAT-YC. They were also invited to provide any additional comments about the ranking process or survey generally, in order to provide more context to their selections. Three professionals and one young carer left comments. Two professionals reported the challenging nature of ranking the items; the other professional stated they had not chosen their items according to the tasks a young carer might undertake, as they felt it was more important to focus on potential impact from the caring role. The young carer's comment was more of an observation that many young carers may be unaware they need help or support, or that it was available.

The top ten items ranked by mean were tabulated and full tables (42 and 43) for each cohort are provided in Appendices 15 and 16. Table 44 on the following pages provides details of the total sample's top ten items, ranked by the overall mean scores. Out of the 16 items sent to the panel, each cohort chose the same eight items in their final top ten. Three items each were from Topics 1, 2 and 3 respectively. There was one item from Topic 5 and there were no items in the top ten from Topic 4. This is perhaps not surprising, as the overall ranking of topics by the expert panel placed Topic 5 as second to lowest and Topic 4 as lowest for importance.

It is important to note that the qualitative findings from all of the data throughout the survey were significant to the overall analysis and final selection. The item ranked second overall in the top ten *(...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?)* was changed slightly to *'...if they need support with their own health or emotional wellbeing, e.g. counselling, advice on coping strategies?* This was in response to previous comments in the qualitative data suggesting young carers are often unaware of, or may neglect, their own health needs. Further slight adjustments to the wording of items will be considered and discussed following consultation with participants in the final phase of the study.

Table 44: Top 10 ranked items by the expert panel (n=19) for inclusion in the CAT-YC

Topic** (& original Item No. within topic)	Top Items ranked by overall Mean: How important is it to ask the young person...	Ranking Position	Mean Ranking* (SD)
2 (9)	...if they are undertaking tasks they don't want to do?	1	**3.13** (2.85)
3 (2)	...if they need support with their own health or emotional wellbeing, e.g. counselling, advice on coping strategies?	2	**4.00** (2.81)
1 (9)	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	3	**5.15** (3.61)
5 (4)	...if there is anything that could help reduce stress/anxiety at or about school/college?	4	**5.43** (1.74)
3 (3)	...if they have a friend or family member they can speak to or contact for help or support?	5	**5.67** (3.13)
1 (3)	...if they have support from another adult in the home?	6	**5.92** (4.17)
1 (4)	...if they need support to continue their caring role?	7	**6.20** (4.62)
2 (1)	...about the type of things they do to help in their caring role?	8	**6.33** (4.27)
3 (6)	...if they want a break or time away from their caring role?	9	**6.93** (3.67)
2 (6)	...if they are giving medication to the person they care for, or checking it has been taken?	10	**7.00** (4.43)

*Items were ranked from (1) as the highest ranked item, so the items ranked highest have the lowest mean.

** **Topic 1:** Understanding the Caring Situation
Topic 2: Details of the Care Provided by the Young Person
Topic 3: The Young Carers Own Health and Social Wellbeing
Topic 4: The Young Carers Identity and Self-Esteem
Topic 5: Education and Future Plans

6.9 Chapter Summary

In this chapter, the recruitment process, demographic details, data collection, qualitative and quantitative analysis and findings from rounds two and three of the Delphi survey were presented. Similarly, details and findings from a fourth round by an expert panel consisting of young carers and key individuals from national and regional organisations working with young carers, were presented. Their purpose was to review the final 16 items and select and rank the final top ten items for inclusion in the pilot version of the CAT-YC. The next chapter discusses the final phase of the study, which involves the development of the 'next steps' section of the CAT-YC, together with a guide for practitioners, and an evaluation of a small validity pilot study to test the readability and usability of the tool.

Chapter Seven

Findings from Phase Three

7.1 Introduction

This chapter presents the findings from the final phase of the study. The first part of the chapter begins with an explanation of how the top ten items for inclusion in the CAT-YC, discussed in the previous chapter, were incorporated into a draft version of the tool for piloting. Information is provided about the development of additional sections of the tool, and a separate user guide for staff. Details are given about a consultation exercise conducted with professionals and young carers to further refine the CAT-YC and user guide for staff. In the second part of the chapter, the evaluation of a brief pilot study conducted by three organisations working with young carers is discussed. The recruitment process, demographic details of the participants, data collection, analysis and findings from the evaluation are reported. Further adjustments to the tool following the evaluation are discussed and the chapter concludes by presenting a full version of the final CAT-YC.

7.2 Developing the Pilot Tool

The first part of this phase aimed to address the third study objective, which was:

3. *To consult with young carers and professionals on the pilot version of the CAT-YC to finalise format, instructions and wording*.

Prior to consulting with professionals and young carers, an initial draft copy of the CAT-YC was created, based on similar design principles to those of the original CAT (Knighting et al. 2015, 2016). Six sections were developed to include:

Section 1: space to record demographic details

Section 2: the top ten items to identify and screen young carers for any potential needs

Section 3: an alert thermometer to record the number of high or medium alerts

Section 4: space for suggested next steps guidance

Section 5: space for planning and action points

Section 6: space to record details of the next review, consent data and signature

The first section of the draft CAT-YC was developed to include space for the young carer's demographic information, education details, parent or guardian's contact details, family composition and basic pertinent information about the person they cared for. The second section contained an initial identifying question to ascertain if the young person was providing care for a family member, followed by the top ten items from the findings in phase two. Section three contained the alert thermometer from the original CAT to record the number of high or medium alerts (Knighting et al. 2015, 2016). Section four had a suggested next steps section for staff, with space to include appropriate guidance for addressing each item scoring a high or medium alert in section two. Section five had space to record up to four priority alerts requiring action together with boxes for any immediate action taken, next steps, name of the person responsible for following up the action, and a date for when the action would be followed up. The final section had space for when and who would conduct the next review, information regarding consent for use of data and space for the young carer's signature.

Similarly, a user guide for staff was developed to explain how to administer and complete each section of the tool. Information was also included in the guide to remind practitioners to refer to any appropriate safeguarding policies and to discuss storage and sharing of the CAT-YC, according to their own organisational policies and procedures. Finally, researcher contact details were provided for further information or guidance if required.

7.3 Consultation Exercise

Gatekeepers at four groups who had taken part in previous phases of the study were approached in March 2019 and invited to take part in a brief pilot study to assess the readability and usability of the CAT-YC. It was reiterated that this would involve their organisations conducting a pilot study themselves, which would then be evaluated afterwards following interviews with staff members and young carers who had taken part. All were keen to participate, and meetings were arranged with each group to discuss the draft version of the CAT-YC and the user guide for staff before the pilot study commenced later the same month. Altogether, four members of staff and two young carers (n=6) took part in the consultation exercise.

7.3.1 Changes following Consultation

Participants from each organisation were enthusiastic about the draft version of the CAT-YC and the young carer participants particularly liked the colour and format. They also felt that having it on one double-sided sheet of A4 made it more appealing than if it had been over several pages. Changes and refinements to four of the six sections of the CAT-YC were suggested, and one change to the user guide for staff. Each of these changes and refinements will be considered in turn.

7.3.1.1 Section One of the Draft CAT-YC

In section one of the CAT-YC, staff requested an additional space in the heading to record an ID Code or Registration number for organisational purposes. Additionally, space to record the young carer's G.P. contact details and any relevant medical information was requested within the demographic details. Due to the number of young carers living in large families, more space was requested for information about who lives in the family home. Staff also asked for a space under the parent/legal guardian's details to record if there are any barriers to them being contacted, e.g. if they do not have parental responsibility for the young person. A final request was for space to record any additional or significant information about the cared for family member.

7.3.1.2 Section Two of the Draft CAT-YC

Section two had the most significant changes. The initial identifying question of '*do you currently have any needs or concerns about providing care, or about your own health and well-being?*' was felt by staff to be too confusing, as some young carers do not associate their role with providing care. It was suggested this question be changed to '*do you currently have any needs or concerns about looking after someone in your family who needs support, or about your own health and well-being?*' Similarly, young carers had been asked to rate each of the ten screening items by circling high, medium or low need emojis after being asked '*do you feel worried about or need help with...'* followed by the screening item. This was felt by staff to be too closed and might encourage low need responses. A more open '*how much help or support do you need with...'* was suggested as an alternative question to precede the

screening items. However, both staff and young carers taking part in the consultation liked the use of red, amber and green emojis in the scoring system.

The item asking about support with '*your own health or emotional wellbeing, e.g. counselling or advice with coping strategies'* was felt by staff to be leading, and might encourage the young person to focus only on counselling, therefore '*e.g. counselling or advice with coping strategies'* was removed. It was suggested that two of the ten items '*getting support with caring from another adult in the home'* and *'speaking to a friend or family member for help or support'* could be combined and replaced with '*speaking to someone about getting support with your caring role.'* The item '*continuing to provide care, if that is what you want*' was felt to be unnecessary in the list of screening items, as it was asked again in a later part of the tool. This created two spaces in the screening section, therefore the findings from the Delphi survey and expert panel were reviewed again.

The item that had been ranked 11th overall by the expert panel ('*if they want or need help to make staff at school/college aware of their caring role'*) was felt to be covered by the accepted item asking about '*anything that is stressful about school or college'*. Participants felt asking a young carer that question would naturally lead into a conversation about whether school staff were aware of the caring situation at home. Similarly, the item ranked 12th by the expert panel (*'if they need support with their physical health*') was felt to be adequately covered now by the item asking *'about your own health or emotional wellbeing'*.

The item ranked 13th overall by the expert panel *'if they feel bullied or stigmatised by others because of their caring role'* was not felt to be covered by any of the other accepted items, therefore, this item was added to the screening list. However, both staff and young carers did not like the phrase *'stigmatised by others'* and suggested this was changed to '*lonely*' before inclusion in the CAT-YC. The items ranked 14th, 15th and 16th were also felt to be adequately covered by items already accepted by the expert panel in their final ten items.

Staff at all four organisations felt it imperative that a screening item was included that might help identify if the young carer was caring for more than one family member. This was felt

necessary due to the increasing number of young carers referred to them who undertook caring responsibilities for separated parents, grandparents and extended family members, as well as siblings. Although the item '*if they are looking after siblings, due to a parent's poor health'* had been ranked 16th overall in the Delphi survey and had therefore not been sent to the expert panel for review, staff suggested this may have been higher if the item had been worded more inclusively than just siblings. Therefore, following the consultation exercise an item '*supporting or caring for anyone else in the family*' was added to the remaining space in the screening items section in the CAT-YC for piloting.

7.3.1.3 Sections Three to Six of the Draft CAT-YC

There were no changes or refinements proposed to section three of the CAT-YC, which was the alert thermometer to record medium or high alerts. In section four, staff agreed that the guidance given in the suggested next steps section needed to be generic for different organisations and would be most useful to professionals who do not work with young carers all of the time. Suggestions for this section focused on encouraging the young carer to talk about their role and needs, providing information and support, and signposting to appropriate services. Section five also did not illicit any changes and just one change was suggested for section six; to add space for whether a follow up review was to take place by phone or face-to-face.

7.3.1.4 User Guide for Staff

The user guide for staff was felt to be straightforward and easy to follow. Just one change was suggested, which was to clarify that scoring should be based on need or perceived need. Therefore, if a young carer scored an item on the CAT-YC as low or no need, but the staff member felt this might not be the case and their health or wellbeing was at risk, they should use their professional judgment to adjust the score. They also appreciated the reminder in the guide to refer to appropriate safeguarding policies if required. Once all of the information from the consultation exercise had been actioned, new draft versions of the CAT-YC and user guide for staff were produced for the pilot study.

7.4 Recruitment for the Pilot Study Evaluation

The consultation exercise provided necessary and useful feedback about the CAT-YC. However, it was important for the tool to be used in practice in a pilot study to see if any further changes needed to be made. As discussed in Chapter Four (Methods), the pilot study was conducted by young carers' organisation themselves, before an evaluation was undertaken in order to address the final study objective, which was:

4. *To explore the experiences of young carers and professionals when using the CAT-YC.*

As in previous phases of the study, a purposive sampling approach was undertaken to recruit participants (Green and Thorogood, 2014; Bryman, 2016). Gatekeepers at the four organisations who took part in the consultation exercise were given copies of the updated pilot version of the CAT-YC and user guide for staff in March 2019, along with study documentation to disseminate to members of staff and young carers who expressed an interest in taking part in an evaluation of the pilot study. They were asked to recruit staff and young carers to evaluate using the CAT-YC as part of their own organisational pilot study. One organisation was unable to conduct the pilot study and subsequently recruit participants within the time-frame for this phase of the study, therefore, participants were recruited from three organisations.

7.4.1 Participant Demographics

Six members of staff and ten young carers were invited by gatekeepers to take part in the evaluation. Altogether, six members of staff and four young carers (n=10) took part in the evaluation. Tables 45 and 46 on the next page provide anonymised demographic participant information for staff and young carers. All participants worked or lived in North West England and all stated their ethnicity to be White British. Young carers had a mean average of four years of experience in their caring role, with the median starting age being 12. Staff had a mean average of eight years of experience working with young carers.

Table 45: Demographic Profile of Staff (Evaluation)

Characteristics	n=6	Characteristics	n=6
Gender		**Job Title**	
Female	5	Young Carers Support Worker	5
Male	1	Young Carers Project Worker	1
		Length of Time in Role	
Ethnicity		1-2 years	1
White British	6	5-6 years	3
		9 years or more	2

Table 46: Demographic Profile of Young Carers (Evaluation)

Characteristics	n=4	Characteristics	n=4
Gender		**Main Care Recipient**	
Female	3	Mother	3
Male	1	Father	1
Age		**Reason for Recipient Needing Care**	
15	1	Physical Health Condition	3
16	1	Physical Disability	1
17	2	Mental Health Condition	2
		(**Some participants selected more than one reason for needing care*)	
Ethnicity			
White British	4	**Length of Time in Caring Role**	
		3-4 years	2
		5-6 years	2

7.4.2 Data Collection for Evaluation

Young carers and staff who agreed to participate in the evaluation were invited to take part in individual face-to-face interviews; young carers aged 16-18 and staff were also given the option for the interview to be by telephone. Prior to the interviews, participants were asked to read and sign a consent form (if a face-to-face interview), or provide verbal audio recorded consent over the telephone and asked if they had any questions before proceeding. Interview questions had been developed and structured to focus on addressing the final study objective, referred to in section 7.4 earlier. Open questions were followed by targeted probing, in order to facilitate discussion and elaboration of answers (Tod, 2015). Separate

interview schedules for staff and young carers were used to aid this process and are included in Appendices 17 and 18. Altogether, two interviews took place by telephone with staff and the remaining eight interviews took place face-to-face at young carers' centres. Interviews were digitally recorded and lasted between 6 minutes and 24 minutes, with a mean average time of 11 minutes.

7.4.3 Data Analysis for Evaluation

As discussed in Chapter Four (Methods), a content analysis approach was used to analyse transcribed data collected from participants in this phase (Hsieh and Shannon, 2005). However, as highlighted by Elo and Kyngäs (2008), when using content analysis it is important to keep the interview questions in mind and only look for data pertinent to addressing this purpose. Therefore, codes were developed from relevant data identified in the interview transcripts and formed into categories as part of this process (Potter and Levine-Donnerstein, 1999). Three categories were formed during the analysis: Process and Practicalities of Using the CAT-YC; Likes and Dislikes, and Future Use of the CAT-YC. The following section reports findings for each category, with anonymised verbatim quotes from the participants to support the findings, where appropriate. Staff quotes are depicted by the term 'Staff' followed by the number between 1 and 6 attributed to their interview data, e.g. Staff 2; young carers are depicted by the letters YC followed by the number 1 to 4 attributed to their interview data, e.g. YC3.

7.4.4 Process and Practicalities of Using the CAT-YC

The first interview questions focused on the process of introducing and completing the CAT-YC. Participants were asked about the time taken to complete it, clarity and appropriateness of instructions and questions. Time taken ranged from less than 10 minutes (YC1) to 30 minutes (Staff 4, Staff 5), with a median average time of 20 minutes reported. However, this is likely to become quicker with increased use, as one participant reported that:

> *'The first time using it was strange, but by the third time it was easier'*
> (Staff 4)

The instructions on how to complete each section of the tool were generally felt to be clear by staff and young carers:

'Really straightforward to use' (Staff 1)

'Everything was clear' (Staff 3)

'*Nice format to get along with'* (YC2)

In particular, one staff member commented on how the young carers appreciated the use of red, amber and green emojis to indicate high, medium and low levels of need in section two:

> *'It was easy to fill in and the young people liked the faces, rather than having the tick box in the forms we currently use – it's good that it measures the level, rather than just yes/no* (Staff 4)

However, one participant reported that the young person they piloted it with had felt there was too much information on the tool:

> *'They said it was too much, like too busy at first- but they were okay when they actually got going'* (Staff 2)

When asked about the clarity and appropriateness of wording in the questions, all participants except one felt they were clear:

> *'The question on needing support with your health and emotional wellbeing, it didn't flow well. I changed it after the first time to say: "needing help with your health or with how you feel" - it sounded much better'* (Staff 5)

Young carer participants were asked if the questions had helped them talk about any worries or needs they may have. This appeared to have the additional benefit of facilitating reflection about past issues:

> *'Some of the questions jolted stuff in my mind'* (YC2)
>
> *'We talked about my mum's emergency alarm and what I need to do'* (YC3)
>
> '*We spoke about how in Year 8 I got really depressed and didn't see anyone about it when I should have*' (YC4)
>
> '*I think these are good questions that help you talk about different things'* (YC1)

All participants were asked if they felt anything was missing from the CAT-YC, or whether any of the questions led to further discussions about other needs or concerns not currently asked about in the tool. Only one young carer responded to this question:

> *'Maybe add a question about stress in general, not just in school or college'* (YC2)

This was also implied by a staff participant, who stated:

> *'Yes, we spoke about emotions and the emotional side of caring – that wasn't on the form – maybe ask is there anything else you want to tell me?'* (Staff 2)

One staff participant felt that a question was needed somewhere on the tool to record whether anyone else in the family shared caring responsibilities, reflecting that this conversation occurred as a result of a discussion with a young person about their parent's perception of whether they were providing care or not. Participants were asked about the type of actions or next steps that were taken in response to any of the alerts in section two of the CAT-YC. Two young carer participants reported that:

> '*Yes, (staff member) is going to ring my form teacher and talk about my maths'* (YC4)

> *'One of the things for me to do is check if the youth group is doing Duke of Edinburgh this year. If they are, (YC service) might be able to pay for it'* (YC3)

Hearing a young carer take ownership of one of the suggested next steps was an unexpected finding. However, this may have been influenced by the realisation of a staff member that there was a joint responsibility to making an action plan:

> *'I found the actions all belonged to me on the first couple of times I used it, but then realised the young person could be responsible for some of them, as they were things they could do themselves'* (Staff 4)

Other action points reported by staff highlighted practical solutions taken to some of the issues and concerns raised:

> *'The conversation quickly went to a situation about them being bullied. School weren't aware...we had a conversation with school and it got sorted'* (Staff 2)

'Making an action plan for emergencies was something we could do there and then – it led to putting something in place for a young carer whose mum has epilepsy' (Staff 3)

'I arranged to help a young person create a CV and also talked to their parent about the young person wanting to attend higher education' (Staff 6)

7.4.5 Likes and Dislikes

The practical focus of the CAT-YC was something that the participants unanimously liked, particularly with regards to recording action points and accountability. When asked what they found helpful or useful, young carers reported:

'The plan part and what needed to happen was the most useful thing' (YC1)

'*The action plan was nice to finish off with...it felt like something was happening, not just talking about it'* (YC2)

Similarly, some of the staff participants reported that the section for planning was one of the CAT-YC's best features:

'*Particularly liked Section 5, especially for older young carers...who is responsible and the date, so the young person has it in their head what's going to happen'* (Staff 1)

'*Actually, doing it made me realise some things could be sorted straight away without much effort'* (Staff 5)

'Making a plan together' (Staff 2)

Other positive factors reported by staff related to the CAT-YC's potential for measuring impact, which they felt was more accurate than the tools they currently used:

'We use the MACA and PANOC, but they're too...wishy-washy...I mean some young carers do a lot but aren't impacted and some only do a little, but the impact is really big - being able to measure it and see it is a good idea'
(Staff 3)

There were some features of the tool that participants felt could be improved. Only one young carer suggested an improvement and that appeared to be influenced by their own personal circumstances:

> *'nature of disability section needs to be bigger in my case'* (YC1)

For staff though, a recurrent theme was a lack of enough space to record notes, with one participant also suggesting it would be useful to have space for the young person to write down their own thoughts or information they wanted on record:

> *'I needed to make notes and there was nowhere to make them'* (Staff 4)

> *'I had to write notes separately, and on the side of it – it would be good to have somewhere to put them'* (Staff 5)

> *'Maybe space for the young carer to record their own thoughts or feelings in their own words, or if there's something important they want you to know'* (Staff 1)

7.4.6 Future Use of the CAT-YC

The final category relates to who participants felt would be best placed to complete the CAT-YC with the young person, and how they felt the tool could be used most effectively in practice. The young carer participants appeared less concerned about the profession or role of the person using it with them, suggesting familiarity was a more important factor:

> '*I'd rather it was someone I know, don't care where it's done, as long as it's someone I can trust doing it'* (YC2)

> *'I don't mind who does it, just someone who can talk to me'* (YC4)

> '*Probably someone, anyone at Young Carers' Group...but I'm not that bothered really'* (YC1)

Staff participants were less ambivalent and provided a range of professionals and services they thought could use the CAT-YC:

> *'Schools, CAMHS services, G.P.s - especially for referrals'* (Staff 2)

'Anybody really, ideally it would be good for schools to use this. It would definitely fit in for schools...if it came out as low to medium, they could deal with that themselves and wouldn't need to refer on to us' (Staff 1)

'Best people to use this would be us (Young Carer service) but we need to get schools involved too' (Staff 3)

However, one participant who had initially considered G.Ps, alongside other professionals, then retracted this after further reflection explaining:

'Actually, I don't think a G.P. would have the time to use this – not in a five or seven minute appointment, or whatever you get these days' (Staff 2)

When participants were asked their views on how they thought the CAT-YC could be effective as part of the screening process, interestingly none spoke directly about reduced waiting times for assessment. However, two participants indirectly suggested this could be a consequence from an organisational perspective:

'This would be good to help decide whether Social Services or other agencies need to be involved. I think if professionals use this, they would realise they often don't need to make a referral, so it would prevent unnecessary referrals' (Staff 3)

'It's good for identifying and prioritising areas of need which are directly related to caring responsibilities as opposed to living with a parent who is ill. It's a subtle difference, but for service provision it's important' (Staff 6)

This latter point highlights how some services have minimum thresholds that must be met before they can offer support to young carers. One participant also suggested the CAT-YC could be useful *after* a full assessment too, as part of ongoing monitoring and reviewing any needs that have been identified and actioned:

'Good to use for follow-up reviews, after assessment too' (Staff 5)

Participants were divided in their responses about how often the CAT-YC should be used, with one pointing out that if it may only need to be used once if used purely for triage purposes. However, most of the staff participants felt regular reviews were important, either pre or post

assessment, and gave responses ranging from every three months to every six months. Some participants could not estimate the frequency, suggesting it was entirely dependent on the individual and what action was needed:

> '*If a school used it and identified why a young person was constantly late, for instance, they might put something in place and then want to review it after say a couple of weeks, but for other things it could be longer*' (Staff 3)

> '*Things can shift from one week to the next with some of our young people, so we tend to do reviews either after something's happened or at transition times'* (Staff 5)

Interestingly, the young carer participants were less enthusiastic about how often their needs should be screened. Two declined to estimate a frequency and two said six months and yearly, respectively. Moreover, two could not remember if and when they had been assessed and two said it was more than five years ago, although they thought they had undertaken several reviews since then. In the following section, adjustments made following the evaluation of the pilot study are discussed and a final version of the CAT-YC and user guide for staff are presented.

7.5 Adjustments following Evaluation of Pilot Study

Five adjustments were made to the CAT-YC following the evaluation of the pilot study. The first adjustment was to add an additional question to follow on from the identification question in the heading box of section two. This was to try to ascertain if caring responsibilities were shared with anyone else in the family, or carried out alone. The second adjustment was to amend the wording of the screening item regarding support with *'your own health or emotional wellbeing'* to *'your own health or with how you feel'.* Similarly, the item regarding '*anything that is stressful about school or college'* was extended to become *'anything that is stressful about school or college, or stressful in general'.* The fourth adjustment was to add a reminder after the screening questions for staff to check whether there was anything else the young person wanted to talk about, or record for themselves on the CAT-YC. The final adjustment followed on from this and was to provide space after the

planning section for both staff and young carers to make notes or record pertinent information, if required.

7.6 Summary

This chapter explained how the top ten items for inclusion in the CAT-YC were incorporated into a draft version of the tool to be piloted for readability and usability. Information was provided about the development of additional sections of the tool and creation of a separate user guide for staff. Details were given about a consultation exercise conducted with staff and young carers to further refine the CAT-YC and user guide for staff. After making adjustments, a brief pilot study was conducted by three organisations working with young carers who had taken part in earlier phases of the study. The pilot study was subsequently evaluated, and details were provided about the recruitment process, demographic characteristics of the participants, data collection, analysis and findings from the evaluation. Further refinements were subsequently made and a final version of the CAT-YC was produced.

On the following pages, the final version of the CAT-YC is displayed together with the user guide for staff. The next chapter will discuss how the findings from this and the previous phases of the study were considered alongside existing literature in order to develop this version of the CAT-YC.

7.7 Final Version of the CAT-YC

Carers' Alert Thermometer for Young Carers (CAT-YC)

A short triage tool to identify the needs of young carers and plan support

Edge Hill University

SECTION 1: Young Carer's Details **ID/Reg No:**

Date CAT-YC conducted.....

By: (Staff name) .....

Young person's name.....

Known as.....Gender.....

Age..... Date of birth.....Ethnicity.....

Address.....

.....

Contact number(s).....

G.P.s name/contact no.....

Medical information (if any).....

School/College .....

School Contact.....

Parent/Guardian's name.....

Parent/Guardian's contact number.....

Any barriers to contact? .....

Are any other agencies involved with the young person or the cared for family member(s)...YES/NO

If YES, please give details of social worker or lead professional

.....

Any current safeguarding concerns? Yes/No/Maybe

Cared for person's name.....

Relationship.....

Nature of illness/disability.....

.....

Who else lives in the family home? .....

.....

.....

.....

.....

Additional/significant information about the cared for: .....

SECTION 2: IDENTIFY & SCREEN YOUNG CARER'S NEEDS

Do you currently have any needs or concerns about looking after someone in your family who needs support, or about your own health and well-being? *(please tick one)* ***Yes*** ☐ ***No*** ☐ ***Unsure*** ☐

If yes, does anyone else in the family share caring responsibilities with you? *(please tick one)* **Yes** ☐ **No** ☐

(*If no needs raised with this opening question continue with the rest of the CAT-YC. If there are needs raised, listen to them now before progressing with the CAT-YC, as it will help to guide you about the young carer's priorities*)

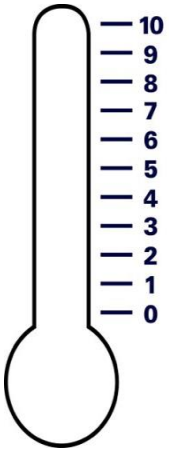
SECTION 3:

Circle the total number of high or medium alerts on the scale

Complete the questions together and circle the level of need or perceived need the young carer has using:

HIGH NEED MEDIUM NEED NO/LOW NEED

	How much help or support do you need with:			
PART A: The Current Caring Situation	**1) ...**any of the jobs that you do in your caring role?			
	2) ...any caring jobs that you would prefer not to do?			
	3) ...making a plan of who to contact in case of an emergency?			
	4) ...giving medication, or checking it has been taken?			
	5) ...supporting or caring for anyone else in the family?			
PART B: Carer Health & Wellbeing	**6) ...**speaking to someone about getting support with your caring role?			
	7) ...not feeling bullied or lonely because of your caring role?			
	8) ...your own health or with how you feel?			
	9) ...having a break or time away from your caring role?			
	10) ...anything that is stressful about school or college, or stressful in general?			
	Sub-total of high and medium alerts			



Check if there is anything else the young person wants to talk about or raise as a concern, or wishes to record themselves on the CAT-YC (*make notes overleaf as appropriate*)

How able do you feel to continue providing care at the current level for the person/people? *(please circle one number on the scale)*	**Not Very Able** 1	2	3	4	**Very Able** 5

SECTION 4: SUGGESTED NEXT STEPS Some general guidance is included below which can be amended by organisations to help guide staff responses when using the CAT-YC, based on local services and support.

Any current safeguarding concerns must be actioned following organisation's agreed procedures

Q1	Encourage young carer to talk about what their caring role involves; provide advice or refer for support if necessary
Q2	Discuss likes/dislikes and consider onward referral to appropriate services, if necessary
Q3	Discuss emergency plan and provide list of names and contact numbers in an easily accessible format
Q4	Discuss concerns; if appropriate, liaise with health and social care professionals
Q5	Encourage young carer to talk about family situation and refer for support as necessary
Q6	Discuss who else (if anyone) supports them (formally or informally) and liaise with or refer as necessary
Q7	Discuss concerns, provide information as necessary and speak to school staff if agreed and required
Q8	Provide information and liaise with appropriate health care professionals, if agreed and required
Q9	Provide information about local groups or services in the community
Q10	Identify concerns and liaise with named contact at school/college, if agreed, or other health and social care professionals, if necessary

SECTION 5: MAKE A PLAN TOGETHER: Use this table to briefly note the details of **up to three priority alerts requiring action now;** any actions taken today, any next steps which have been agreed, who is responsible for them and when they will be reviewed

Brief summary of needs identified by alerts (what would help most at this time)	**Any immediate action taken?** (e.g. info, advice or referral to other services)	**Any next steps required?** (e.g. referral to other services)	**Who is responsible for the next step or follow-up?**	**Date of review or follow up**

Staff Notes:	**Young Carer Notes:**

SECTION 6: Next Review: Agree a review date and who should be responsible for following up the review. All questions must be revisited during a review to monitor the support provided and any change in the alerts.

Date of next review.....**with**.....**by phone or face-to-face**.....

CARER CONSENT FOR USE OF DATA : I consent to the following use of my data from the CAT-YC form:

☐ to enable staff to act on my behalf to get help or support from other services or professionals

☐ anonymous information of the alerts to identify gaps in services or service development

Young Carer's Signature:.....**Date:**.....

7.8 User Guide for Staff

Carers Alert Thermometer for Young Carers (CAT-YC) Staff Guidance

Eligibility Criteria

The CAT-YC is designed for use with young people aged 11-18, who are providing unpaid care for at least one family member at home. The questions have been developed from information provided between October 2017 and April 2019 by 267 young carers and staff working with them.

Procedure

STEP 1: IDENTIFICATION

Ask the young person if they help look after someone at home who would otherwise struggle to manage without their support.

STEP 2: COMPLETE THE CAT-YC

Section 1 - Complete the Young Carers details section

Section 2 – Complete the questions together, circling the level of need or perceived need for any alerts which could impact on the care being provided or on the young carer's own well-being.

 HIGH NEED  MEDIUM NEED  NO/LOW NEED

Section 3 – circle the total number of medium or high alerts on the thermometer.

Section 4 – make a plan with the young carer, prioritising the top three alerts for action and noting the agreed next steps for the priority alerts identified.

Section 5 – set a review date and person responsible for follow up.

STEP 3: IMMEDIATE ACTION

If any of the alerts can be supported immediately, such as provision of information or signposting to sources of support, these should be completed. All other alerts should be included in the action plan indicating the appropriate action and review date.

Please refer to any appropriate Safeguarding Policies if required.

Storage and Sharing of the CAT-YC

Discuss with the young carer where the CAT-YC will be stored and who their information can be shared with, if necessary. Also discuss use of their anonymous information to inform service development e.g. types of alerts identified and any gaps in service provision to meet them.

Ask young carer to sign and date CAT-YC and if under 16, obtain parent/legal guardian's consent, according to organisational policies.

CAT-YC Research Team Contact Details

If you would like more information about the pilot study or have any questions or comments about completing the CAT-YC, please contact Lynn Kettell at kettelll@edgehill.ac.uk or 01695 654353

Chapter Eight

Discussion

8.1 Introduction

In this chapter, the overall findings from the study will be summarised, synthesised and discussed. The process of how the study was conducted has been discussed in previous chapters; therefore, this chapter focuses primarily on the content of the developed CAT-YC tool. The aim of the study was to explore the experiences of young carers aged 11-18 and use their views and professionals' views to develop the CAT-YC, as a short screening tool. The purpose of the CAT-YC is to identify any unmet needs arising from the impact of caring and to triage young carers accordingly for information, support or referral for further assessments. It was important that the CAT-YC was developed using current data, representing contemporary issues and challenges experienced by young carers, rather than relying solely on pre-existing literature. However, it was also important that the views of professionals who work with young carers were taken into account to ensure it contained relevant information for practical use.

Four objectives were proposed to ensure the overall aim was achieved. These were:

1) *To explore the experiences of young carers aged 11-18, and identify factors causing them challenges during their caring experience.*

2) *To seek the views and consensus from young carers and professionals on the items to be included in the CAT-YC.*

3) *To consult with young carers and professionals on the pilot version of the CAT-YC to finalise format, instructions and wording*.

4) *To explore the experiences of young carers and professionals when using the CAT-YC.*

A sequential exploratory mixed method, multi-phased approach was undertaken to address the research aims and objectives, underpinned by a methodology of pragmatism and using a modified Delphi method technique, as referred to in Chapters Three (Methodology) and Four

(Methods). The study design was similar to that used in the development of the original Carers' Alert Thermometer (CAT) for adult carers (Knighting et al. 2015, 2016), with a qualitative first round of the Delphi used to identify and form items from participants and the literature (Keeney, Hasson and McKenna, 2011; Jünger et al. 2017). However, the data collection methods were adapted in phase two by having two methods of distributing the Delphi survey: an online survey for participants aged 16 and over, and through small group meetings for younger participants aged 11-15 (Greene and Hogan, 2005; Morris et al. 2015; UK Council for Child Internet Safety, 2016).

This chapter starts by providing a recap of the reasons for developing the CAT-YC, and how the methods used were the most appropriate way of addressing the study's aim and objectives. Each section of the CAT-YC will be considered in turn, with particular emphasis given to the importance of the screening items in section two. Existing literature will be drawn upon to support all aspects of the discussion, thereby providing a comprehensive rationale for the decisions taken throughout. The chapter concludes by considering the potential benefits of using the CAT-YC for young carers, cared for family members, relevant professionals, and organisations working with young carers.

8.2 Recap of Reasons to Develop the CAT-YC

As noted in the first two chapters of this thesis, a gap was identified in existing practice; the lack of an effective tool to identify and triage unmet needs in young carers aged 11-18, of a family member with a long term or progressive illness or disability. Relevant legislation was considered, together with the statutory duty of local authorities in the UK in carrying out an assessment of young carers' needs, in order to prevent or minimise any negative consequences from the challenges of caring (Department of Health, 2014). It was established that these duties are often devolved to non-governmental third sector or charitable organisations, and confusion over who has responsibility for identifying, screening and assessing young carers for any unmet needs was noted (ADASS, 2015; Leu and Becker, 2017). Moreover, it was indicated that following changes in legislation, particularly from the implementation of the Care Act (2014) and Children and Families Act (2014), increased awareness of young carers by professionals had resulted in more referrals for assessment,

with some services consequently having to employ long waiting lists (Carers Trust, 2016b). However, it was also argued that '*despite the legislative changes, young carers' needs assessments are still inconsistently applied and lack rigorous screening procedures'* (Aldridge, 2017:9).

Existing literature about young carers was reviewed in Chapter One to try to understand the impact of caring. It was acknowledged that although young carers are often highly motivated to help their families, they may not recognise the emotional as well as physical toll the role can take on their health and wellbeing, and professionals were urged to take a more proactive stance in ensuring needs assessments are carried out in a timely and systematic manner (The Children's Society, 2016; Leu and Becker, 2017). This was suggested to be particularly challenging due to assessments being so resource intensive and a report by the Children's Commissioner (2016:19) noted that *'depending on the complexity of the case, an assessment can take two days.'* However, it was also confirmed that there is currently no national standardised assessment process for young carers in the UK, and it was implied that long waiting times from referral to assessment were therefore commonplace (The Children's Society, 2016). This was argued to be particularly pertinent, following a policy review that highlighted the effects of economic restraints and cuts to funding for youth services (Aldridge, 2017).

A review of existing screening and assessment tools developed for use with young carers was undertaken and discussed in Chapter Two. Key points related to the limitations in some of the studies reviewed; either in the methods used, lack of validity and reliability data, or in the items in the tools themselves. Furthermore, the review highlighted that as only one tool, the OCINI (Nicholls et al. 2016), had been developed empirically in the UK following the implementation of the Care Act (2014) and Children and Families Act (2014), there may be different considerations that influenced the development of some of the tools reviewed, either due to prior or alternative legislative regulations, or because of different socio-economic factors (Aldridge, 2017). Additionally, none of the studies reviewed reported how long it took, or was likely to take, to administer the tools developed. Moreover, none of the tools in the studies reviewed offered signposting or suggestions for possible further

assessments, actions or interventions. All of these factors provided a rationale for a new empirically developed, evidence based short screening tool that could be used proactively to identify and triage for unmet needs in young carers, and subsequently provide the opportunity for signposting, ongoing monitoring and review.

8.2.1 Needs Assessment Findings in this Study

Following on from the above discussion, it was evident from the brief scoping exercise undertaken with staff from five young carers' organisations in the UK, as reported in Chapter Two, that representatives felt a more standardised referral, screening and assessment process would be useful. This was in response to questions about the current processes and tools they used, and it was acknowledged by respondents that assessments could be lengthy and time-consuming. Funding cuts, reductions in staffing levels, and an increasing reliance on volunteers were also reported as contributing factors to long waiting lists. Findings from the exercise confirmed that approaches to screening and assessment in the UK are often inconsistent, with many organisations having to be creative in finding methods and locally created tools that work effectively for them.

Throughout each phase of the study, participants frequently reported the low number of young carers who had either had, or were aware of having had, an assessment of their own needs. In phase one, findings in the qualitative data confirmed that many young carers had not had an assessment. Analysis of data from 13 young carer participants found that five had never had an assessment, two were unsure whether they had ever had one, four reported having an assessment between two and six years ago, and only two participants had been assessed within the last year. In phase two, the majority of participants (80% of 28 young carers and 100% of 68 professionals) rated the importance of assessing young carers' needs as either very or extremely important on a five-point Likert scale, with no participants from either cohort rating it as unimportant. It was also evident from the findings that the majority of participants (52% of young carers and 65% of professionals) thought that young carers' needs should be regularly reviewed every three to six months.

Similarly, in the final phase of the study, half of the young carers had never had an assessment, and the majority of participants from both cohorts thought that young carers' needs should be reviewed every three to six months. Findings from this phase indicated that young carers preferred an assessment or review to be conducted by somebody they were familiar with, and this will be discussed in more detail later in the chapter. Prior to this, consideration is given to responding to a call by some of the leading key academics involved in the field of young carers to undertake more targeted research.

8.2.2 Response to a Call for Research

A recent narrative review of research, practice and policy about young carers argues there is a need for large scale quantitative studies with representative samples to be conducted, to investigate the extent and nature of impact from caring (Joseph et al. 2019). The authors of the review suggest that small scale regional qualitative research studies involving participants from a dedicated young carers' centre have, to a certain degree, reached data saturation (Joseph et al. 2019). However, in response to this, it should be noted that although the initial qualitative phase of this study in the first round of the Delphi survey was conducted in one region, it included six participants who were not part of a dedicated young carers' service. This provided new information not previously reported in existing literature, e.g. the impact on a young carer's emotional wellbeing from having paid carers in the family home, as noted in Chapter Five (Phase One Findings). Furthermore, in the second and third rounds of the Delphi survey, 251 responses (n=101 young carers; n=150 professionals) were collected and analysed from participants in every region in England, as well as from Scotland, Wales, Ireland, Canada and the USA, with a further 10 participants taking part in the evaluation of the pilot study in phase three.

Moreover, Joseph et al. (2019) argue that there is a need for more well-established tools that allow comparisons to be made between young carers and their peers. In response to this, it is argued that the CAT-YC will be able to facilitate this need as it will focus on the impact from caring, thereby differentiating between everyday helping carried out by many young people, and those who are in a caring role. Additionally, monitoring the number and nature of referrals made will not only provide useful statistical data, but may aid understanding as to

which interventions are potentially the most effective. Further implications for using the CAT-YC in research, policy and practice will be considered in more detail in the final chapter.

8.3 Development of the CAT-YC

As referred to in the previous chapter, the CAT-YC consists of six sections and is presented on a double-sided single sheet of A4. The size of the tool was particularly welcomed by participants in the final phase of the study, who also appreciated the clear format and layout of the separate sections. The screening items in section two were presented in two parts which related to the two overarching themes developed from data findings in Round one (R1) of the Delphi survey, as supplemented by existing literature. The two themes were the current caring situation (part A), and the young carer's own health and wellbeing (part B). The importance of having the items listed in this way is primarily for more sophisticated research and assessment purposes, where a more detailed pattern of any impact experienced by young carers may be required. Again, this may be beneficial for future research, practice and policy implications. However, it is also important to note that when participants were asked to rank the five topics, or sub-themes, according to importance in the Delphi rounds, the caring situation and young carer's health and wellbeing were consistently ranked in the top two as highest priority.

8.3.1 Section 1 of the CAT-YC

The main purpose of section one of the CAT-YC is to gather demographic information about the young carer, such as their name, address, date of birth, contact details etc., for administrative purposes. Following the consultation exercise reported in Chapter Seven (Phase Three Findings), several additional items were recorded in this section.

Gender has been reported as an important indicator related to young caring in several published studies and is often noted to be a highly gendered activity (Aldridge, 2014; Nagl-Cupal et al. 2014; Chikhradze, Knecht and Metzing, 2017). Moreover, research involving 79 young carers by Barnardo's (2017) found that young carers were twice as likely to be female than male. Although the gender of participants in phase one of this study was less obviously split, 58% (n=15) girls and 42% (n=11) males, in phases two and three the imbalance was much

more significant. In R2 of the Delphi survey, 75% (n=21) of young carer participants were female; in R3 this was 76% (n=26); R4 (expert panel) was 73% (n=8); and in the pilot evaluation phase, 75% (n=3) of young carer participants were female.

It has been suggested that females are more likely to be seen as a natural carer, when there is a choice between siblings (Becker and Sempick, 2018). Findings from R1 of this study appear to support this supposition, with one participant stating that he had to provide care if his sister was not available. Therefore, it is important for practitioners to not lose sight of gender-specific differences, so that girls are not automatically drawn into a caring role when there is a choice (Chikhradze, Knecht and Metzing, 2017). Recording the young carer's gender on the CAT-YC provides useful statistical information for organisations, but may also be helpful when planning support or resources. For instance, findings in a study involving 50 young carers suggested that female young carers were more likely to experience low self-esteem than male young carers (Abraham and Aldridge, 2009). One strategy to address this may be to provide targeted support for females by organising activities that aim to increase self-esteem.

Ethnicity is another important issue related to young caring; it has been argued that families with a culturally and linguistically diverse background may have more difficulties accessing support and services (Nagl-Cupal et al. 2014). Moreover, a study by The Children's Society (2013) found that young carers were 1.5 times more likely to be from black and minority ethnic communities than their peers, and twice as likely to not speak English as their first language. All of the young carer participants in phases one and three of this study reported their ethnicity as White British. This is most likely to be due to the specific regional nature of data collection and is a study limitation that will be reflected on in the final chapter. However, in phase two, data was collected from participants nationally. In this phase 25% (n=7) in R2 and 24% (n=7) in R3, of young carer participants stated their ethnicity was not White British, reflecting a more ethnically diverse sample.

The study by The Children's Society (2013) referred to on the previous page also indicated that young carers are 1.5 times more likely to have a medical condition or learning disability themselves than their non-carer peers. This finding would benefit from future research to

explore this correlation more, to see if there is a causal link from either the physical and emotional effects of caring, external societal factors such as poor housing conditions or inadequate nutrition from a greater likelihood of young carers living in a low income household (Dearden and Becker, 2004; The Children's Society, 2013), or from the general vulnerability of families that have difficulties seeking support (Butler and Astbury, 2005; Becker and Sempick, 2018). Again, recording these details on the CAT-YC will provide useful statistical information for organisations, but may also help when planning future research or strategies for targeting resources more effectively.

School or college details, together with a named contact, were important considerations across each phase of this study. An example of how this might be useful in practice occurred during the evaluation of the pilot study in phase three, when one staff member from a young carer's centre discussed how they had contacted school staff about a bullying situation and the issue had been immediately resolved. Similarly, the importance of liaising with school staff has been reported in existing literature (Thomas et al. 2003; Butler and Astbury, 2005; Warren, 2007; Moore, McArthur and Morrow, 2009). Moreover, in research commissioned by the Department for Education, problems balancing school, homework and the caring role were found to be more evident where school staff were unaware of a young carer's situation at home (Aldridge et al. 2016). However, in R1 of this study, findings from several young carer participants implied they did not want their teachers to know details about their home life, unless it was on their own terms. Similarly, qualitative comments from young carers in R2 and R3 opined the importance of professionals only contacting school staff if they have the young person's permission.

An important question in section one of the CAT-YC seeks to establish whether any other agencies are involved either with the young person or their cared for family member. This is important for several reasons: to help gauge the level and extent of any support already provided (if any); to liaise with other professionals as part of a whole family approach; and to help ascertain whether there may be any safeguarding implications that need consideration. The first point should not detract from the need for young carers to receive their own support, regardless of any support given to other family members (Thomas et al. 2003; Joseph et al.

2019). The second point relates to information in section 6.65 of the Care and Support Statutory Guidance, issued under the Care Act (2014), that advocates for local authorities to take a holistic view of a person's needs, and to identify how the cared for person's need for care and support impacts on all family members (Department of Health, 2014). The last point, as noted in Chapter One, enables local authorities to delegate almost all of their functions under section 79 of the Care Act (2014), with the main exception being safeguarding (Carers UK, 2016). Therefore, if a potential safeguarding issue is raised, this should automatically trigger the legal requirement to conduct a full needs assessment by a qualified social worker (Local Government Association, 2018).

The final questions in section one relate to details of the health condition or disability of the cared for family member, and who else lives in the family home. This may not just provide an insight into the caring situation at home, but could again be a potential flag for safeguarding concerns. Previous literature highlights how parental mental health conditions can be particularly challenging for young carers to cope with, due to the unpredictability of the nature of the condition and resultant extent of care support required (Cree, 2003; Aldridge et al. 2016). Other literature reports that young carers are more likely to struggle caring for a parent with drug or alcohol related issues (Thomas et al. 2003; Doutre, Green and Elliott, 2013). In relation to young people caring for a parent with a drug related problem, professional participants who took part in the final phase of this study highlighted the safeguarding concerns that sometimes came not so much from the caring activities undertaken, but more from having unknown adults visiting the family home.

Many young carers live in a lone parent household where a mother is the care recipient (Abraham and Aldridge, 2009; Nagl-Cupal et al. 2014; Aldridge et al. 2016). This could indicate an increased likelihood of the young person being a primary carer, and the amount and type of caring undertaken appears to correlate with there being no other adult in the home (Aldridge et al. 2016). Furthermore, it has been reported that health care professionals sometimes discharge patients with care needs from hospitals to households with only children to care for them, with little or no support from professionals (Barnardo's, 2017). It is

suggested therefore, that health care professionals check who will be providing care, particularly when discharging female patients who have children under 18 (Barnardo's, 2017).

Findings in this study confirmed that many participants care for a lone parent, and therefore may have increased caring responsibilities. In R1 of the Delphi survey, 14 of the 26 participants lived in a lone parent household and the majority (12 of the 14) participants were caring for their mothers. Similarly, mothers were listed as the main care recipients by 64% (n=18) of young carer participants in R2, 59% (n=20) in R3, and 91% (n=10) in R4 (Expert Panel). Moreover, in the consultation exercise in phase three, professionals at all four organisations confirmed the increasing number of young carers referred to them who live in large families. It is essential therefore, for professionals working with young carers to try to understand the family circumstances and household dynamics when carrying out a screening. A final item in section one of the CAT-YC is for additional or significant information about the cared for family member to be recorded. This could be used to record practical considerations, such as whether there are language or communication difficulties, or perhaps if there is a terminal diagnosis, or hospital admission or discharge planned.

8.3.2 Section 2 of the CAT-YC

Section two of the CAT-YC begins with a question to identify whether a young person is a carer for a family member or not. This is because existing literature, as reported in Chapter One, suggests that many young carers do not necessarily identify with being a carer (Smyth, Blaxland and Cass, 2011; Doutre, Green and Knight-Elliott, 2013; The Children's Society, 2013). Findings from R1 of this study indicated that all but one of the participants did identify with the term, however this is unlikely to be representative of all young carers due to most of the sample being recruited from dedicated young carers' centres. Establishing whether a young person is undertaking a caring role may be particularly useful for professionals who do not work exclusively with young carers, e.g. school staff, social services and health care practitioners. Interestingly, in a study involving 800 teachers, almost half of the respondents said they did not feel confident they could recognise a young carer, and 34% felt there were known young carers at their schools who were not being adequately supported (Barnardo's,

2017). This highlights the need for greater awareness and training for school staff about young carers.

The literature review undertaken and reported in Chapter Two found that only one tool, the YC-QST-20 (Aldridge, 2014), aimed to identify hidden young carers and that tool had not been empirically developed or designed to ascertain any impact from caring. Additionally, the question in section two of the CAT-YC asking whether the young person shares caring responsibilities with another family member may provide an indication of how much responsibility they have, and consequently how much free time they may or may not have. It has been argued that causes of familial strain can largely be explained by the absence or failure of other family members to contribute to care, resulting in less time for the young carer to pursue other activities (Stamatopoulos, 2018). However, this is not equivocal and it must be acknowledged that increased strain within the family can also come from a lack of sufficient external health and social care support (Aldridge et al. 2016). Indeed, findings in R1 of this study highlighted that support can come from other sources, such as paid carers and health and social care professionals. Again, asking this information will help provide a more holistic picture of the whole family situation that may be useful when planning support or interventions. In the following sub-sections, each screening item of section two will be considered in turn.

8.3.2.1 Item 1:

How much help or support do you need with any of the jobs you do in your caring role?

In order to understand whether, or how much, help or support is needed to reduce any impact from the caring role, it is important to first establish the type of caring activities undertaken. As noted in Chapter One, young carers can engage in a variety of types of physical and emotional caring activities and these can impact on many areas of a young carer's health and wellbeing (Aldridge and Becker, 1993; Thomas et al. 2003; Dearden and Becker, 2004; Warren, 2007). Similarly, wellbeing can be compromised from having less opportunity to pursue hobbies and friendships (Aldridge et al. 2016; Cheesbrough et al. 2017). Young carers may also miss school in order to attend medical appointments with their ill or disabled family member, and consequently this can negatively impact their education (Moore, McArthur and

Morrow, 2009; Becker and Sempick, 2018). By establishing a better understanding of the type of care given, advice or signposting to appropriate support can be provided. However, it has been argued that this must also be balanced with the need for local authorities to be responsible for providing adequate support to the ill or disabled family member, without having to rely on young people to fill any gaps in care (Warren, 2007; Aldridge, 2017; Barnardo's, 2017; Leu and Becker, 2017; Joseph et al. 2019).

Findings from each round of this study reported a multitude of caring activities undertaken that concurs with the findings in existing literature, and several suggestions were made by participants about factors or resources that were, or might be, helpful in increasing skills and confidence in the caring role. In R1, several young carer participants reported they would like practical training such as learning first aid. Similarly, in R3, one young carer said they would like practical training in lifting and positioning their parent. However, it was also confirmed in this round that caring often develops insidiously over time and the cumulative effects may not always be apparent until discussed. In R2, one professional participant reported that their initial query when meeting a young carer for the first time was whether or not there was a need for a crisis intervention. This makes it essential that questions about the caring role are asked at the screening stage, to ascertain the level of any potential impact.

Moreover, although it is important to establish whether and/or how much help or support is needed, professional participants in R2 cautioned against making unrealistic promises of support, due to the increasing lack of available resources. This point was also raised by the Children's Commissioner (2016), who noted that capacity is a common barrier for many local authorities as they are increasingly being asked to do more with less. However, it was also argued that insufficient resources are not an excuse for not getting the job done, and this will be a challenge for local authorities to negotiate when planning budget spending (Children's Commissioner, 2016). As noted above, the responsibility for providing care should not rely on family members and they must have a choice about what and how much support they are willing, and able, to contribute (Aldridge, 2017; Joseph et al. 2019).

8.3.2.2 Item 2:

How much help or support do you need with any caring jobs that you would prefer not to do?

One of the key principles highlighted in the Care and Statutory Guidance issued under the Care Act (2014), paragraph 2.49, is that children should not undertake inappropriate or excessive caring roles that have an impact on their development. It is argued that a young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life (Carers Trust, 2016a; Children's Commissioner, 2016). Legislation is not categoric about what is classed as inappropriate or excessive, however it is likely to include providing personal care such as dressing, washing, helping their family member in or out of the bath or shower, toileting (Dearden and Becker, 2004; Abraham and Aldridge, 2009), but could include changing a stoma bag or cleaning a stoma area (Aldridge et al. 2016). It could also include helping manage household finances (Cheesbrough et al. 2017) or administer medication or physiotherapy (The Children's Society, 2013). Therefore, establishing whether there are caring activities that a young carer does not want to do may give a better understanding of what might be deemed inappropriate.

In R1 of this study, some participants talked about the personal care they provided for their parent and one male participant revealed how he did not want to do it, but felt obliged to; another described providing support with toileting as horrendous. However, it should be noted that providing personal care is not the only type of task some young carers find difficult and there may be other caring activities that they do not want to do for other reasons, e.g. because it restricts their time for leisure activities, or even from sleeping adequately. In R2 and R3, professional participants reiterated the importance that caring should be a choice, not an obligation and that young people have a right not to care, regardless of age. One young carer participant in R2 noted the importance of asking this screening question, in order to see whether the young carer felt they were being pushed out of their comfort zone. Likewise, one professional participant in R2 felt asking this question may indicate whether the young carer was being abused, or at risk of abuse. Therefore, medium or high need responses to this screening item could raise a potential safeguarding or child protection alert, and if there are

concerns that the child may be at significant risk of harm, a safeguarding referral should be made immediately (Local Government Association, 2018).

8.3.2.3 Item 3:

How much help or support do you need making a plan of who to contact in case of an emergency?

This item had one of the highest consensus levels in the Delphi survey with 91% (86 out of 95 participants) rating its importance for inclusion as equal to or greater than a median level of 4 (*very important*) on a Likert scale of (1)-(5). It was also ranked third for importance by the expert panel, indicating its significance for inclusion in the CAT-YC. Findings from existing literature also confirm the importance of having an emergency or crisis plan, and this was rated second in a list of helpful factors in a study by the Children's Commissioner (2016). However, none of the screening or assessment tools in the studies reviewed in Chapter Two contained a question about this. Of course, some long-term health conditions can be stable and it has been argued that in those circumstances young carers will have a clearer understanding of their family member's likely health and care needs (Stamatopoulos, 2018). However, for others, the health condition affecting their family member might not be static and could fluctuate either due to the nature of the condition itself, or its management or treatment (Cree, 2003; Warren, 2007). In these cases, outside support may be less readily available; therefore, it is imperative that young carers have a plan of what to do or who to contact in an emergency, if the need arises. This is particularly important for those living in a lone parent household.

It has been argued that young carers often carry out roles that in the general workforce would usually be carried out by trained and qualified adults, who have a high level of specialist skill and knowledge (Joseph et al. 2019). Therefore, when young carers are providing care, there could be an unintentional risk of harm to their family member in an emergency situation, arising from a lack of medical knowledge and training. This links with findings reported in Item 1 above, whereby some young carers requested first aid training. However, although this would undoubtedly be useful for some young carers, there may be other types of emergency situations that require a different type of response or action. For instance, a parent

experiencing a severe psychotic episode will not necessarily need first aid administering, but may not recognise they need urgent support from the community psychiatric team, or other relevant health professionals.

In R1 of this study, several participants recalled situations when they had been worried about the health of their family member and had been unsure what to do. Similarly, findings in R2, R3 and R4 indicated that young carers are often unaware of what support is available and how to access it. Therefore, it cannot be presumed that they would know what to do in an emergency situation. In the pilot study evaluation in phase three, one young carer participant recalled how being asked this question had given them the opportunity to discuss an action plan if their parent's emergency alarm went off. Likewise, a professional participant reported making an emergency action plan with a young carer they had piloted the CAT-YC with, and appreciated that asking this screening item had enabled a quick and easy way of responding to a potentially difficult situation.

In the consultation exercise in phase three, professional participants reiterated the importance of having a plan in place and various strategies were discussed, such as having a list of relevant phone numbers by the landline or on the fridge door, or keeping the phone numbers in the young carer's, or their parent's, mobile phone. Neither of these options were considered ideal in an emergency, as lists can be lost and phones can run out of battery charge or be password protected. However, importantly, asking the question at the screening stage about what to do and who to contact in case of an emergency provides the opportunity to initiate a conversation and make a plan that would be helpful if ever faced with a particularly challenging situation.

8.3.2.4 Item 4:

How much help or support do you need giving medication, or checking it has been taken?

Existing literature reports that some young carers help with either administering medication to their ill or disabled family member, by reminding them to take it, or by checking that is has been taken (The Children's Society, 2013; Aldridge et al. 2016). This has been argued to be a matter of concern by the Royal College of General Practitioners (RCGP, 2011). As noted in the

last item, most young carers lack medical knowledge and training (Joseph et al. 2019). This, coupled with possibly providing care over long hours and experiencing disturbed sleep patterns, could be dangerous for both the young carer and their family. Administering medication has also been listed as a potentially inappropriate task in paragraph 2.49 of the Care and Statutory Guidance issued under the Care Act (2014).

In R1 of this study, several young carer participants revealed that they were responsible for administering medication, and one stated that they frequently get up in the middle of the night to do so. Moreover, one participant reported the difficulties they had obtaining prescribed medication from a pharmacy. One strategy that could be used to address this issue would be to arrange for a young carer and their family to obtain a Young Carers Authorisation (Medicine Collection) Form. This acts as a written agreement between the person named on the prescription and the pharmacy, so that the young person can collect any prescribed medication on their behalf (Carers Trust, 2018).

In R2, one professional participant highlighted the risks that could come from a young carer either accidentally overdosing the person receiving care, or from potentially taking medication themselves. Further dangers related to younger siblings having access to medication, if not stored correctly or left unattended. Similarly, in R3, young carer participants noted the importance of making sure medication was correctly administered, with one recognising that giving the wrong medicine could kill the person cared for. All of these points could raise a potential safeguarding alert under section 17 of the Children Act (1989) and therefore the young carer's response to this item must be considered carefully by the professional undertaking the screening.

8.3.2.5 Item 5:

How much help or support do you need supporting or caring for anyone else in the family?

As reported earlier, many young carers live in a lone parent household where a mother is the care recipient (Abraham and Aldridge, 2009; Nagl-Cupal et al. 2014), and this could indicate an increased likelihood of the young person being a primary carer (Aldridge et al. 2016). Moreover, it has been reported that young carers are 1.6 time more likely to live in a

household where there are three or more children (The Children's Society, 2013). Again, this could increase the likelihood of young carers caring for more than one person, as they may undertake childcare responsibilities in addition to their caring role. Alternatively, they may be providing care for an ill or disabled sibling as well as caring for a parent (Nagl-Cupal et al. 2014).

Conversely, it has been suggested that young carers in single-child families may provide a greater level of care than those in large families, as they do not have siblings to share caring tasks with (Stamatopoulos, 2018). However, it is not known whether young carers in single-child households are more likely to be caring for a lone parent, or for more than one adult. Therefore, it is important to establish whether a young carer is supporting more than one family member, as this may give an indication of how much time is spent caring. As reported previously, it has been argued that there is a correlation between the amount of time spent on caring activities and negative outcomes from the impact of caring (Dearden and Becker, 2004; The Children's Society, 2013; Cheesbrough et al. 2017).

In R1, five of the participants talked about caring for more than one family member; for three of them this was for a parent and sibling, and for two of them it was caring for both parents. Interestingly, three lived in a dual parent household and two lived in a lone parent household, although it is not known whether the two participants caring for both parents had siblings or not. In the consultation exercise in phase three, respondents confirmed they were increasingly receiving referrals about young carers who were caring for more than one family member. Often this occurred within the same family home and was usually for a parent and sibling(s), but also included young people who were caring for separated parents, grandparents or extended family members who lived in a different home. This also reiterates the importance of asking this information in order to help provide a more holistic picture of the whole family situation, which may be useful when planning support or interventions.

8.3.2.6 Item 6:

How much help or support do you need speaking to someone about getting support with your caring role?

Existing literature suggests that many young carers do not ask for an assessment of their own needs (The Children's Society, 2013; Aldridge et.al. 2016; Children's Commissioner, 2016). As noted in Chapter One, this may be due to them not self-identifying as carers (Carduff et al. 2014; Phelps, 2017), or because they fear repercussions for their families if they ask for help (Thomas et al. 2003; Abraham and Aldridge, 2009). It may also be that they are unaware of their entitlement to ask for an assessment or support (Aldridge, 2017; Leu and Becker, 2017). Additionally, many young carers struggle to ask for support even when they are aware of it (Aldridge et al. 2016), and it has been argued that they are less likely to seek support from others when feeling stressed, because disclosing distress involves revealing negative thoughts (Bolas, Van Wersch and Flynn, 2007; Moore, McArthur and Morrow, 2009).

Again, as noted earlier, it may be more likely that young carers in lone parent families do not seek help as they are less likely to have another adult in the family home to ask about support (Aldridge et al. 2016), or because they do not want to feel that they have let their parent down (Rose and Cohen, 2010). Findings in R1 of this study indicated that five out of the six participants who were not part of a dedicated young carers group lived with both parents, suggesting that having two adults in the family home may be a protective factor against needing help asking for support.

Moreover, it has been argued that some family doctors and health care practitioners do not always recognise a young carer's involvement in caring for a family member (Thomas et al. 2003), and are therefore unlikely to ask if a young person in the family has needs of their own from the impact of caring. This is likely to extend to school staff, as it has been reported that over 50% of 800 teachers in a YouGov survey feel young carers hide their situation from teachers (Barnardo's, 2017). Therefore, if many professionals themselves are unaware of the legislative rights to identify and support young carers, it is unlikely that young carers or their families will be aware (Leu and Becker, 2017). For some young carers, having a written document, such as a carers ID card, may prove useful for situations where they are reluctant

to disclose their home situation. Recent research found that carers ID cards can be particularly helpful for young carers to use in schools, GP surgeries and shops, and prevent the need for giving lengthy explanations about their circumstances (Local Government Association, 2018).

In R1 of this study, findings indicated a reluctance by some participants for school staff to know about their caring situation. Similarly, in R2 and R3 several young carers reported that they did not want to be asked in-depth questions about their family situation. This highlights the importance of ensuring that if the CAT-YC is being used by someone in school, it must ideally be by someone the young person feels they can trust; either a dedicated teacher or another member of staff. However, it may be that some young carers do not know who to approach, or how to access support. Findings in phase three highlighted how one young carer knew they needed to see someone about feeling depressed but had not felt able to. Existing literature reports how some young carers find it difficult to talk to professionals about their caring role through fear of being taken into care (Thomas et al. 2003; Aldridge et al. 2016). Findings throughout each phase of this study support this notion, albeit indirectly; many young carers said they wanted to keep their caring situation within the family, or that it was nobody else's business. Therefore, it is important that professionals using the CAT-YC are sensitive to answers given when this screening item is asked.

8.3.2.7 Item 7:

How much help or support do you need with not feeling bullied or lonely because of your caring role?

Feeling bullied or stigmatised by others were recurrent themes in existing literature about young carers and findings from each phase of this study support this assertion. It has been reported extensively that young carers can experience loneliness and isolation because of their caring role (Warren, 2007; Richardson, Jinks and Roberts, 2009; Rose and Cohen, 2010; The Children's Society, 2013; Barnardo's, 2017). This can impact on opportunities to take part in social activities, which consequently reinforces feelings of isolation (Bolas, Van Wersch and Flynn, 2007). These feelings may then be compounded by a fear of rejection and can contribute to young carers distancing themselves from others, thereby restricting their social participation further. Given the limited social opportunities some young carers have

experienced, it is perhaps unsurprising that they sometimes misinterpret social cues and conversations when they are with others (Moore, McArthur and Morrow, 2009; Bayliss and Collins, 2013).

Findings in Chapter One noted a sense of confusion of non-caring peers' motives when asking about their family member's health, suggesting that some friends do not understand their situation, and could be cruel when talking about their ill or disabled family member. Similarly, being made to feel different because of other people's reactions to their caring role has been reported, and this extends into bullying and name calling in some instances (Butler and Astbury, 2005; Earley, Cushway and Cassidy, 2007). In R1 of this study, several participants talked about their difficulties with friendships, often questioning the motives of friends who asked questions about their home life or family. Similarly, some participants revealed that they avoided talking to non-carer friends in case they were made fun of or seen as different.

Existing literature confirms that young carers have good reason to be cautious, e.g. in one study, 45% of 51 young carers could identify times when they had been directly teased or assaulted because of their caring role (Moore, McArthur and Morrow, 2009). It has also been argued that young carers are more likely to feel stigmatised when caring for a parent with a severe mental health condition, or drug or alcohol related issue (Cree, 2003; Abraham and Aldridge, 2009). It is imperative therefore, that professionals using the CAT-YC are alert to how bullying can manifest from isolation or stigma attached to the role, and respond accordingly. In the final phase of this study, one professional participant reported they had been able to quickly resolve a bullying situation that a young carer was experiencing, following using the CAT-YC in the pilot study.

It has been suggested that many young carers value the support of their peers, and describe young carers' groups as helpful for making friends (Richardson, Jinks and Roberts, 2009). Having something in common with other young carers, and the opportunity to discuss issues in a safe space has been reported to be a protective factor for reducing isolation (Aldridge et al. 2016; Barnardo's, 2017). Therefore, asking this item at a screening stage will not only help understand whether a young carer is feeling stigmatised or lonely, but will provide the

opportunity to signpost them to relevant local young carers groups, if they are not already attending one. However, it is also important to note that one participant in R1 of this study felt lonely because they were unable to spend as much time with their parent as they would like, as their parent frequently stayed in hospital to be with the young carer's ill sibling. Therefore, professionals using the CAT-YC need to be sensitive to the responses given when asking this screening item, and not focus solely on impact from potential bullying.

8.3.2.8 Item 8:

How much help or support do you need with your own health or with how you feel?

As noted in Chapter One, young carers can engage in a variety of types of caring activities that can impact on many areas of a young carer's health, such as emotional difficulties from anxiety about their family member's health (Earley, Cushway and Cassidy, 2007), sleeping or eating difficulties (Cree, 2003) or stress from their caring situation (Bolas, Van Wersch and Flynn, 2007). Moreover, there are often physical aspects to providing care that can impact on a young carer's health, such as from lifting or assisting with mobility (Aldridge et al. 2016; Stamatopoulos, 2018) and these can result in backache and tiredness (Nagl-Cupal et al. 2014). Findings in the literature suggest that worry and fear about their own and their family member's health are amongst the most frequently mentioned health concerns young carers experience (Cree, 2003; Thomas et al. 2003; Nagl-Cupal et al. 2014). Moreover, in a recent survey of 40 young carer practitioners, 100% of participants had worked with young carers who had self-harmed, 97% had worked with young carers who had experienced panic attacks, and 76% of practitioners felt most or all of the young carers they worked with had suffered from anxiety, anger and isolation (Barnardo's, 2017). Similarly, 45% of 295 young carers self-reported that they had a mental health problem in a recent survey (Becker and Sempick, 2018). However, in common with other types of informal carers, many young carers report putting their own health needs behind those of the person they help care for (Barnardo's, 2017).

It is therefore important to try to understand how the emotional toll of caring can impact young carers, and how they can cope with often overwhelming emotions. The Theory of Cognitive Adaptation suggests that various coping strategies are often employed to

counteract the negative impact of distress on wellbeing (Taylor, 1983). This theory is supported by findings in existing literature suggesting that many young carers have developed different coping strategies to lessen the impact from caring, such as from engaging in social activities, sharing their feelings with others, or journaling their thoughts (Aldridge et al. 2016). Likewise, it is important to try to understand how the physical toll of caring can impact young carers, as undertaking the role can expose them to potentially short and long-term physical injuries (Nagl-Cupal et al. 2014; Stamatopoulos, 2018). Moreover, as noted in section 8.3.2.3, young carers can carry out tasks that are usually carried out by trained and qualified adults (Joseph et al. 2019); however, as their role is unpaid and voluntary, there are no health and safety workplace mechanisms in place to support them.

In R1 of this study, one participant talked about how counselling had been helpful for them. Others talked of coping strategies such as playing computer games or watching TV. In R2, however, one professional participant highlighted the difficulties in accessing counselling in some areas. In R3, one professional participant pointed out the importance of asking a young carer about their own health as part of the screening, as it was a good indicator of whether they were sleeping and/or eating healthily, which could not only negatively impact their health, but also their attendance at school or in social activities. However, as noted earlier, this should not deter professionals from making appropriate referrals when necessary, and challenges with availability should not be a reason to not make them (Children's Commissioner, 2016). Recording these details on the CAT-YC will also provide useful statistical information that may help when planning how to target young carer recognition and support from health care practitioners, as evidence from this study and others (e.g. Barnardo's, 2017) show this has often been lacking.

8.3.2.9 Item 9:

How much help or support do you need with having a break or time away from your caring role?

Many young carers report that they want some time away from their caring role, and peer support allows young carers to socialise and discuss issues with people who are having similar experiences (Barnardo's, 2017). Dedicated young carers groups in particular are an important

source of support and respite for some young carers, and it is argued that having something in common with others makes it easier for them to open up in conversation about caring (Aldridge et al. 2016). In addition to this, they can be helpful for having time away from their caring role, and provide the opportunity for young carers to engage in activities they would not be able to do otherwise (Richardson, Jinks and Roberts, 2009). It is also reported that they can provide important information, advice and advocacy (Aldridge et al. 2016).

However, there may be difficulties with transport to attend these groups, particularly for those living in rural areas (Butler and Astbury, 2005; Warren, 2007). Moreover, as findings from R1 of this study noted, not all young carers want to attend dedicated young carers groups, and some prefer to engage in alternative activities with their non-carer peers. Others reported that playing computer games, listening to music, or watching TV gave them a break from their role. It has also been suggested that school itself can be an adequate source of respite from their role (Moore, McArthur and Morrow, 2009; Clabburn and O'Brien, 2015). Additionally, it must be acknowledged that even with time off it may be difficult for some young carers to switch off from their role, and findings in existing literature indicate that some young carers experience anxiety or anticipatory anxiety about their family member's wellbeing when they are away from them (Earley, Cushway and Cassidy, 2007).

Furthermore, it has been argued that providing respite to young carers as a means of support can perpetuate a caring situation and fails to address the real problem, which is that many families lack appropriate and effective interventions that would prevent young people from having to provide care in the first place (Doutre, Green and Elliott, 2013; Aldridge, 2017). Nevertheless, as noted previously, young people will still want to provide care and support, regardless of how much external support the family are receiving (Thomas et al. 2003; Chikhradze, Knecht and Metzing, 2017). Moreover, as noted in Item 7 earlier, many young carers have difficulties with friendships and can experience loneliness or isolation, making it vital that they have access to appropriate and relevant resources and support that can help them.

In R1 of this study, although some young carer participants reported they preferred to take part in their own non-carer related activities, the majority of participants confirmed the importance to them of attending young carer groups, both for the opportunity to interact with others and for the respite they offered. However, findings in R2 confirmed that many young carer organisations are unable to provide many respite activities, due to funding and resource issues. It is important therefore, to be pragmatic about the availability of respite when signposting to local groups in the community, and have knowledge of other potential sources of support that could be useful with having a break from the role.

8.3.2.10 Item 10:

How much help or support do you need with anything that is stressful about school or college, or stressful in general?

Problems for young carers at school have been reported extensively in existing literature, including struggling to keep up with schoolwork and homework, and missing deadlines (Thomas et al. 2003; Bolas, Van Wersch and Flynn, 2007; Moore, McArthur and Morrow, 2009; Department for Education, 2016). It has been argued that young carers are ten times more likely to be regularly late for school than their non-caring peers, and absent five times more often (Cheesbrough et al. 2017). Moreover, preoccupation and tiredness when in school have been frequently reported, which is perhaps not surprising given the additional responsibilities many young carers have (Smyth, Blaxland and Cass, 2011; Aldridge et al. 2016; Barnardo's, 2017). In the short term, this can affect engagement and concentration in lessons, but also has long term implications; it can contribute to young carers achieving significantly lower educational attainments at GCSE level at age 16, equivalent to nine grades lower overall than their peers (The Children's Society, 2013). In turn, this is likely to affect future educational opportunities, career aspirations and job opportunities.

It has been argued that young carers are a vulnerable and disadvantaged group and as a result they will have specific needs to which schools must respond (Office for Standards in Education, Children's Services and Skills (OFSTED), 2015). There are a number of ways schools and colleges could support young carers and it has been suggested this could be by providing personalised teaching or pastoral support, access to homework or after school clubs, or by

being flexible regarding punctuality and attendance (Aldridge et al. 2016). It may be that some young carers find it difficult to see beyond their immediate situation, and it has been recommended that careers advisors in schools are trained to be aware of the challenges young carers face when making decisions about post-compulsory education, so that they can offer relevant advice and support (Barnardo's, 2017). Additionally, there could be an implicit reluctance from parents to discuss future education and career options with their children (Aldridge et al. 2016), making it even more important that young carers can access appropriate help and advice.

Findings from the Delphi survey in this study support the findings in existing literature and this item had the highest level of consensus, with 94% (90 out of 95 participants) rating its importance for inclusion in the CAT-YC as equal to, or greater than, a median level of (4) (*very important*) on a Likert scale of (1)-(5). In R1, several participants talked of the difficulties they had completing homework, which was compounded by a sense that teachers did not believe them. As noted in section 8.3.1 earlier, some young carers are reluctant for school staff to know the details of their caring situation. Therefore, when asking this screening item consideration must be given to establishing how much, if any, information is disclosed to school staff. Another participant in this round confirmed they wanted to attend higher education but had not spoken to their parents about it. Similarly, in R3, one professional participant acknowledged that some young carers struggle to discuss life beyond compulsory education with their parents. This was reported by another professional participant to be an action point for them to address, following using the CAT-YC with a young carer in the pilot study in the final phase. It is therefore essential that young carers have the opportunity to discuss and consider their options with relevant and informed advice from educational professionals when considering their futures.

Findings from the evaluation of the pilot study in phase three suggested that young carers would appreciate being asked whether they were experiencing anything stressful in general, and not just in school or college. Likewise, in R1 of this study two young carer participants talked about the stress of their family member being in hospital and not knowing when, or even if, they would come out. As noted earlier, existing literature reports that many young

carers have difficulties sleeping, and worry about the health of the person they care for, as well as worrying about the uncertainty of their own future (Cree, 2003). Moreover, they are less likely to seek support from others when feeling stressed (Bolas, Van Wersch and Flynn, 2007; Moore, McArthur and Morrow, 2009). Therefore, asking this item at the screening stage will help gauge any impact from the caring role which will be useful for planning strategies and resources for support.

8.3.3.11 Final Part of Section 2 of the CAT-YC

A reminder is included at the end of this section to check if there is anything else the young person wants to talk about, raise as a concern, or record for themselves. Additionally, there is a question asking the young carer to rate on a Likert scale of (1)-(5) how able they feel to continue providing care at the current level. This rating question was added to all versions of the CAT in 2017 and helps indicate whether the caring situation might be at risk of crisis, and to monitor any changes in carer resilience over time.

It has been argued that young people should not undertake caring tasks or provide informal support at all, as it falls under the responsibility of local authorities to provide adequate support to the ill or disabled family member needing care (Aldridge 2017; Barnardo's, 2017). However, it must be acknowledged that it can sometimes be difficult to distinguish between the impact on a young person from caring, and the impact from living in a family where there is long term illness or disability (Thomas et al. 2003; Warren, 2007; Doutre, Green and Knight-Elliott, 2013). Moreover, as some health conditions are episodic in nature and resultant care needs can fluctuate, it is perhaps unrealistic to expect that external support or resources will always be readily available when needed (Cree, 2003; Aldridge, 2017).

In R3 of this study, a salient point was raised about the importance of asking the rating question, indicating that continuing care should never be assumed, even though it often is. Findings in R2 indicated that this was particularly important during the transitional ages of 16-18 when young carers are planning their own futures. Similarly, findings in the evaluation of the pilot study in phase three confirmed the importance of asking this during transitional times, and also checking whether there was anything else the young carer wanted to talk

about. Answers to all of the questions in this section will help the professional carrying out the screening to establish the extent of any unmet needs for the young carer, within the broader context of the family situation at home.

8.3.3 Section 3 of the CAT-YC

The main purpose of this section of the CAT-YC is to provide a visual reminder of any alerts raised. Findings in existing literature suggest it is not just individual issues experienced by young carers that are problematic, but the interconnectedness of issues that should be of concern to professionals working with them (Cree, 2003). Therefore, having a visual thermometer that displays the number of alerts raised serves as a clear overall indicator of the level of unmet needs. This is supported by findings from the evaluation of the pilot study in phase three, whereby one professional participant reported that measuring the level of alerts was preferable to ticking yes or no boxes. Moreover, comparisons with another tool were made by one professional participant in this phase, who argued that the CAT-YC was more useful as it could measure the level of impact, rather than just the caring activities themselves.

Recording the type of alerts is also likely to be useful from an organisational perspective, as it will assist in planning what kinds of advice, support or interventions are required. Findings from this phase of the study also suggested that having an alert system would be particularly helpful to staff working in schools; if no/low need answers are given to the items during screening and are therefore not recorded as alerts on the thermometer, this may reduce unnecessary or inappropriate referrals. Apart from the obvious benefits for individual young carers, the benefits of this for professionals and organisations are two-fold: triaging according to priority may help reduce waiting times for assessment for those young carers with the highest amount of need, as discussed in the brief scoping exercise undertaken and reported in Chapter Two; and for planning and resource purposes when considering threshold levels for support and service provision, as reported in the pilot study evaluation in Chapter Seven.

8.3.4 Section 4 of the CAT-YC

It has been argued that one of the barriers to accessing support can be from a lack of understanding of the types of support available (Aldridge et al. 2016). Therefore, the

importance of having a suggested next steps section is valuable for all professionals working with young carers, but particularly more so for those that do not see them regularly, such as school staff, social workers or health care practitioners. Suggestions for next steps could trigger more appropriate referrals, resulting in timely support and less likelihood of unnecessary referrals, as discussed in the previous section. It may also help clarify if there are safeguarding issues that need further consideration or actioning under section 17 of the Children Act (1989).

Findings from the consultation exercise in the final phase of this study highlighted the importance of having reasonably generic next step suggestions that could be adapted by different organisations according to their own requirements. The main focus of the suggestions were to encourage the young carer to talk about their caring role, and to liaise with, refer or signpost to other professionals for more targeted support. It is therefore important for practitioners using the CAT-YC to have local knowledge about resources available, in order to signpost effectively, and not raise expectations where services may not be available.

8.3.5 Section 5 of the CAT-YC

Findings from the evaluation of the pilot study in the final phase indicated that both young carers and professionals felt this section of the CAT-YC was particularly useful. As reported earlier, young carers can be exposed to numerous risks, and a lack of medical knowledge and training can contribute to those risks. Moreover, as unpaid carers they will not have insurance, registration with professional bodies, or support from employers in case of difficulties (Joseph et al. 2019). It is therefore imperative that any needs identified are not just actioned accordingly, but are also recorded in writing together with details of any action taken. Space is also provided on the CAT-YC to record any key needs and further actions that may be required, and details of who will be responsible for follow up and monitoring. Moreover, this feature is missing from all of the screening and assessment tools that were reviewed in Chapter Two.

Findings in the final phase indicated the importance of including space for both professionals and young carers to note additional information. For professionals, this is mainly for pragmatic reasons, however for young carers it provides the opportunity to record their thoughts, feelings or needs in their own words. This is vitally important, as young carers possess a unique understanding of their own family situations and caring roles, making it crucial that they are heard and their views are considered, alongside their family members (Phelps, 2017). This supports the principle of the whole family approach that seeks to protect young carers from undertaking excessive or inappropriate caring (Department of Health, 2014). It also supports Article 12 of the UN Convention on the Rights of the Child, that every child has the right to express their views, and these should be considered when decisions are made that involve them (Gov.UK, 2010).

8.3.6 Section 6 of the CAT-YC

The final section of the CAT-YC records the date of the next review, who it will be with and, following feedback in phase three of this study, whether it will take place by phone or face-to-face. It also has space for the young carer to give written assent to the use of their data in order to obtain relevant support, and additionally to inform service developments. The importance of regular reviews cannot be underestimated, as the impact from caring can increase unexpectedly due to changing family circumstances such as divorce, household composition etc., but also from the fluctuating health condition of the care recipient. This was confirmed in R2 and R3 of the study, whereby several professionals reported on how impact can change frequently due to some of the family members illnesses. Similarly, in phase three, findings from the evaluation of the pilot study reiterated the importance of regular reviews and the need to be flexible regarding the frequency with which they occur.

8.4 Use of the CAT-YC

The purpose of using the CAT-YC as a short screening tool is to be proactive rather than reactive. Therefore, its use will provide information about any unmet needs a young carer may have from their caring role that can be triaged for advice, support or referral according to priority, thereby reducing the likelihood of a crisis intervention. Additionally, it provides the opportunity for ongoing review and monitoring, and may also be useful for evaluation

purposes for organisations when planning service delivery. It is clear that prevention, mitigation and support require a range of disciplines and professionals to be involved, within different multi-disciplinary teams and settings, and the User's Guide for Staff in Chapter Seven, section 7.8, contains straightforward instructions on how to use the CAT-YC. The findings across all phases of this study highlight the wide scope of uses and potential users of the CAT-YC.

As reported in Chapter Six, findings in R2 indicated that professional and young carer participants felt the most appropriate professionals to use the CAT-YC should be: young carers' centre staff; social workers; teachers; anyone who has contact with young carers, and other school staff. Less popular options included G.P.s, practice nurses, school nurses and adult workers supporting a parent. Other suggestions for who could use the CAT-YC included online support services, school counsellors, Children's Early Help Services and youth workers. It was also suggested that the CAT-YC could be used as a self-reporting tool, although this would not provide the opportunity for ongoing monitoring or review. Similarly, findings from the expert panel in R4 confirmed that the CAT-YC was suitable for various professionals to use, with an additional suggestion of the child and adolescent mental health service, CAMHS. Mental health and drug and alcohol services that support parents were also suggested by Barnardo's as potentially useful groups for identifying and signposting young carers (Barnardo's, 2017).

Findings from the evaluation of the pilot study reiterated the importance of involving schools as part of the identification and screening process. A potential benefit of this could lead to providing more targeted resources and support, and a reduction in inappropriate referrals to social services. As well as benefitting individuals, this is important from an organisational perspective because some services have minimum thresholds to meet before they can offer support. The following section discusses further potential benefits of using the CAT-YC, for young carers, care recipients, individual practitioners, and organisations.

8.5 Benefits of the CAT-YC

A common theme throughout this study has been the importance of early intervention and the role that all services that work with young carers have in identifying, assessing and supporting them, so that they have the best opportunities to flourish. This is congruent with the principles and guidance set out in the legislative framework that promotes the need for professionals to consider young carers' needs, as part of a holistic whole family approach. For young carers themselves, the potential benefits from using the CAT-YC are that it makes the screening process visible, promotes autonomy by engaging them in making a plan together, and consequently legitimises their support needs. For the care recipient, the potential benefits are likely to come from knowing their child is being supported, reassurance that others are aware of the caring situation and are trying to help, and are engaging as part of a whole family approach, as advocated by the Department of Health (2014).

For individual practitioners, the potential benefits of using the CAT-YC are likely to come from being proactive in trying to avert a crisis, or recognising when a safeguarding referral needs to be made to Social Services under section 79 of the Care Act (2014). Moreover, the items and information in the CAT-YC will help act as a reminder of what to ask young carers during the screening and will also provide signposting information and suggested next steps that will help formulate a plan of action. This will be particularly useful for practitioners who do not work with young carers all of the time, e.g. school staff. Appendix 19 contains an email from a large national children's charity, stating that both their own staff and schools feel the CAT-YC will fill the gap needed to identify and support young carers. For organisations, completing the CAT-YC will provide a clear record of activity that will assist with accountability. It will also generate statistical data that will be useful for auditing and communication purposes, but will additionally help establish which interventions are most effective. This in turn will help when planning resources and service delivery. A final benefit is that it demonstrates the organisation's commitment to supporting young carers, which may also be strategically important if they are a third sector or charitable organisation applying for funding.

8.6 Summary

This chapter started by providing a recap of reasons for developing the CAT-YC, and how the methods used were the most appropriate way of addressing the study's aim and objectives. Each section of the CAT-YC was then considered in turn, with particular emphasis given to the importance of the screening items in section two. Findings from each phase of the study were summarised and synthesised with existing literature to support all aspects of the discussion. The chapter concluded by considering who is best placed to use the CAT-YC, and what the potential benefits of using it could be for young carers, cared for family members, relevant professionals, and organisations that work with young carers. In the final chapter, the implications of developing the CAT-YC will be considered further, along with recommendations for future research, policy and practice. Moreover, the strengths and limitations of how this study was conducted will be discussed, together with its original contribution to knowledge, before final conclusions are drawn.

Chapter Nine

Study Summary

9.1 Introduction

The main aim of this chapter is to highlight the strengths and limitations of the study, thereby adding transparency and credibility to the thesis. The chapter starts by outlining the criteria used to evaluate the quality of how the study was conducted and reported, before using this as a framework to provide structure to the chapter. Following this, a summary is provided of how the key findings have made an important original contribution to knowledge, both topically and methodologically. Recommendations are proposed for future research, policy and practice, before the chapter concludes with some final words about the study.

9.2 Evaluating the Study

It has been argued that all research studies must be open to critique and evaluation, and this is an essential pre-requisite of the application of findings (Long and Johnson, 2000). Therefore, as different approaches were taken to collect and analyse data, as discussed in Chapter Three (Methodology), two frameworks have been used to support the evaluation. The first is based on guidance given on conducting and reporting Delphi studies (CREDES) (Jünger et al. 2017). A full extract of the recommendations is provided in Appendix 20, but Figure 14 below sets out the titles of the four domains and 16 items included in the guidance.

Recommendations for the Conducting and Reporting of Delphi Studies (CREDES)	
Rationale for the choice of the Delphi technique 1. Justification **Planning and design** 2. Planning and process 3. Definition of consensus **Study conduct** 4. Informational input 5. Prevention of bias 6. Interpretation and processing of results 7. External validation	**Reporting** 8. Purpose and rationale 9. Expert Panel 10. Description of the methods 11. Procedure 12. Definition and attainment of consensus 13. Results 14. Discussion of limitations 15. Adequacy of conclusions 16. Publication and dissemination

Figure 14: Recommendations for the Conducting and Reporting of Delphi Studies (CREDES) (Jünger et al. 2017)

Although the CREDES recommendations given by Jünger et al. (2017) were developed in the context of palliative care, they have been applied in this study due to the absence of other existing guidelines for conducting Delphi surveys. However, as the Delphi method was modified by using qualitative data in round one, as reported in Chapter Four (Methods), and also in the evaluation of the pilot study in phase three, as reported in Chapter Seven (Findings from Phase Three), an additional framework based on the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007) was used to further support the evaluation. A full extract of the COREQ guide is provided in Appendix 21, but Figure 15 below sets out the titles of the three domains and 32 items included in the checklist.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Research team and reflexivity

Personal Characteristics

1. Interviewer/facilitator
2. Credentials
3. Occupation
4. Gender
5. Experience and training

Relationship with participants

6. Relationship established
7. Participant knowledge of the interviewer
8. Interviewer characteristics

Study design

Theoretical framework

9. Methodological orientation and theory

Participant selection

10. Sampling
11. Method of approach
12. Sample size
13. Non-participation

Setting

14. Setting of data collection
15. Presence of non-participants
16. Description of sample

Study design (continued)

Data collection

17. Interview guide
18. Repeat interviews
19. Audio/visual recording
20. Field notes
21. Duration
22. Data saturation
23. Transcripts returned

Analysis and findings

Data analysis

24. Number of data coders
25. Description of the coding tree
26. Derivation of themes
27. Software
28. Participant checking

Reporting

29. Quotations presented
30. Data and findings consistent
31. Clarity of major themes
32. Clarity of minor themes

Figure 15 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist (Tong et al. 2007)

9.3 Strengths of the Study

9.3.1 Rationale for the choice of the Delphi technique

The rationale for using the Delphi technique was clearly set out in Chapter Three. The aim of the study was to explore the experiences of young carers aged 11-18 of a family member who has a progressive or long term illness or disability, and use their views and professionals' views to develop a short screening tool, the Carers' Alert Thermometer for Young Carers, or CAT-YC. It is argued that when justifying the use of the Delphi technique, two aspects are particularly important: the necessity of expert knowledge to co-construct knowledge; and that outcomes can only be as reliable as the available evidence from the participating experts (Jünger et al. 2017). A Delphi survey was chosen as a proven method to gain consensus from both cohorts of participants, who were knowledgeable about the needs of young carers. The methodological underpinning of pragmatism similarly supported the justification of using both inductive and deductive methods to gain consensus through the Delphi technique (Teddlie and Tashakkori, 2009; Tashakkori and Teddlie, 2010).

One of the main strengths of this study has been the involvement of young carers throughout every stage of the process, from informing the study materials to commenting on and providing feedback about the key findings in the final consultation phase (Shaw, Brady and Davey, 2011; Lambert and Glacken, 2011; Phelps, 2017). This is important to note, as existing literature suggests that such active involvement of service users in the research process can have a positive impact on outcomes, by ensuring its appropriateness and relevance (Brett et al. 2014; Dovey-Pearce et al. 2019). Although much has been written about the needs of young carers from either a professionals or young carers perspective, no consensus studies were identified in Chapter One (Introduction and Background) about the prioritising of young carers' needs. Moreover, as reported in Chapter Two (Integrative Literature Review), a systematic approach was taken to reviewing existing literature and identifying screening and assessment tools used with young carers. This highlighted that no consensus studies involving both professionals and young carers in the development of screening or assessment tools of unmet needs had been identified in existing literature. These points further supported the need to undertake a mixed method, multi-phased study to gather the evidence needed to

develop the CAT-YC. This rationale also resonates with guidelines in the COREQ, which outline the importance of researchers documenting their methodological and theoretical orientation (Tong, Sainsbury and Craig, 2007).

9.3.2 Planning and design

Following on from this was the need for systematic recording of the planning of the Delphi survey process, including the development, review and piloting of all the materials used, and transparency about any modifications made (Jünger et al. 2017). As highlighted in Chapter Three, pragmatism places great importance on the research design, as it plays a crucial role in bridging the gap between the research aim and methods used (Morgan, 2014a); thus, being explicit about the planning and design of the study has enhanced its credibility. As noted in the previous section, participants were involved throughout each stage of the process and were consulted about the content and wording of all study documentation. Indeed, even before the study started, potential participants were consulted about their views informally, as discussed in the preface to this thesis; opportunistically, as reported in the brief scoping exercise in Chapter Two; or formally as part of building relationships with gatekeepers, as discussed in Chapter Four.

It has been reported that there are challenges implicit in the pure Delphi technique that regularly lead to it being adapted, in order to fit the needs of the study (Keeney, Hasson and McKenna, 2011; Keeney, 2015). A pragmatic decision was taken to modify the Delphi method for this study, whilst maintaining a clear and explicit focus, with pre-determined criteria for consensus for each round. Modifications made to the Delphi method included having two methods of distributing the Delphi survey: an online survey for participants aged 16 and over, and through small group meetings for younger participants aged 11-15. Another was by the addition of using an extra fourth round with an expert panel to include professionals with a national profile from leading national organisations that support and campaign for young carers, as well as young carers, to review and select the final items for inclusion in the pilot version of the CAT-YC.

The importance of having an agreed, pre-determined criterion for consensus in Delphi studies is reported to be vital for helping to establish rigour and transparency (Keeney, Hasson and McKenna, 2006, 2011). It has been argued that researchers do not always give sufficient attention to group stability or pre-determining the criteria for consensus when they adapt the method and analysis to achieve their study aims (von der Gracht, 2012). Chapters Four and Six (Findings from Phase Two) of this thesis included comprehensive details about the criteria for consensus to accept, reject or re-rate an item in the Delphi survey. Moreover, the criteria were also prominently displayed in tables 26 and 34, in Appendices 12 and 13, respectively. The CREDES guidelines state that ideally the criterion for consensus in a Delphi study should be defined a priori to data collection (Jünger et al. 2017). The initial consensus level for the Delphi survey in this study was set to 70% of participants rating an item as equal to or greater than a median level of 4 (*very important)* on a five-point Likert scale, as had been used in the original CAT study (Knighting et al. 2015, 2016). However, it became apparent on initial analysis that there were very diffuse levels of consensus in the young carer cohort, due to the wide age range and maturity levels of participants, therefore this level was lowered to 60%. Providing a clear guide for what the criterion was and the rationale for how it was selected, enhanced the transparency of the process (Diamond et al. 2014).

9.3.4 Study conduct

Feedback from participants was obtained about the readability and clarity of the survey questions, as recorded in Chapter Five (Findings from Phase One). Likewise, as reported in Chapter Six, prior to launching the Delphi survey a small pilot study was undertaken with representatives from both cohorts of participants, as recommended for Delphi studies by Hasson, Keeney and McKenna (2000) and Novakowski and Wellar (2008). This led to minor modifications to the wording of the survey items, thereby minimising potential bias from the researcher. Moreover, as the CREDES guidelines recommend that attention is paid to how information could influence or bias participants' responses, care was taken to ensure that all feedback given between survey rounds was anonymous. Furthermore, having the young carers aged 11-15 complete the surveys away from home may have reduced the potential for bias through implicit influence, as it has been argued that young people often defer to parents when they are completing surveys online or by post (McDonagh and Bateman, 2012).

The COREQ guidelines highlight the importance in qualitative research of clarifying the personal characteristics of the researcher to the reader, and outlining the relationship and extent of interaction between themselves and their participants (Tong, Sainsbury and Craig, 2007). The preface to this thesis set out the researcher's personal characteristics listed in the COREQ checklist, thereby enabling the reader to assess how these factors may have influenced the interpretation of results in phases one and three of the study, thus adding to the study's credibility. As reported in Chapter Four, young carers can often be reluctant to discuss sensitive issues with others about their caring role and situation (Kennan, Fives and Canavan, 2012; Aldridge et al. 2016). Therefore, a great deal of time was spent establishing an appropriate working relationship with participants prior to collecting any qualitative data, and maintaining these relationships throughout each phase of the study (Lewis and Lindsay, 2000; Polit and Beck, 2017). This involved attending numerous meetings and events, such as a screening of a film made by one young carers' group in Liverpool and a performance in Salford of another group's play, as well as by providing regular updates.

When interpreting and processing results in a Delphi survey, Jünger et al. (2017) recommend using critical reflection to explore any differences in consensus between respondents. This highlighted that young carers' responses to the survey items were more individually focused than the professionals, giving an insight into different areas of concern to them. Moreover, using an additional expert panel in the fourth round of the survey to comment on, choose and rank the final list of items for the pilot version of the CAT-YC may have reduced the potential for researcher bias, by providing a level of external validation of the findings. It is argued that consensus findings from a Delphi survey should be used to help streamline work as an adjunct to meetings, thus allowing the involvement of more individuals (Hasson, Keeney and McKenna, 2000). Reliability and validity were therefore further enhanced by undertaking the consultation exercise prior to the pilot study in phase three, and from the subsequent evaluation of findings afterwards.

9.3.5 Reporting

Rigour has been enhanced by ensuring that all methodological decisions throughout the study were reported clearly and transparently, as evidenced in Chapters Five, Six and Seven. Anonymous demographic details of participants were provided for each phase of the study, along with comprehensive details of the process followed, the methods used and the attainment of consensus (Jünger et al. 2017). Providing demographic information to establish relevance also concurs with recommendations in the COREQ guidelines, and additional details were given about the sampling strategy, method of approach via gatekeepers, and sample size (Tong, Sainsbury and Craig, 2007). Chapter Four reported extensive information about the setting of where data were collected, and this illustrated another strength of the study. Existing literature reports the difficulties researchers often face trying to recruit young carers as participants in their studies, resulting in many researchers only recruiting from young carers' centres (Cree, Kay and Tisdall, 2002; Kennan, Fives and Canavan, 2012; Phelps, 2017). As discussed in Chapter Five and Chapter Eight (Discussion), data were collected from six young carers who were not part of a dedicated young carers' service, revealing new information that had not been previously reported in existing literature. This helped reduce any potential bias from purposive sampling of other participants at young carers' centres (Polit and Beck, 2017). Moreover, the wide geographical spread of participants in the second and third rounds of the Delphi survey, ensured the results were representative of each part of Great Britain, thus enhancing generalisability (Bryman, 2016).

One of the key strengths of this study came from the numerous ways that data were collected, including a focus group, individual interviews and a scoping exercise in phase one; three online surveys and six consensus small group events in phase two; and a consultation exercise and individual interviews in phase three. This ensured that participants had a variety of ways to participate, thus enhancing inclusion and engagement, particularly by young carers (Aldridge, 2017; Phelps, 2017). Consequently, an extensive range of data were available for analysis and subsequent reporting. Likewise, in accordance with its pragmatic methodology, data were analysed in different ways according to the requirements of the study phases, including using thematic analysis, descriptive statistics (measures of central tendency, frequency and levels of dispersion), and content analysis. Tables and flow charts displayed or

referred to in Chapters Three to Seven and the Appendix illustrated the process clearly, as recommended in the CREDES guidelines (Jünger et al. 2017).

Comprehensive details of the methods used to collect and analyse data were provided in Chapter Four, in accordance with both the CREDES guidelines (Jünger et al. 2017) and the COREQ guidelines (Tong, Sainsbury and Craig, 2007). In respect of the latter guidelines, it is important to note that transcripts and findings were not returned to participants for validation during data collection or analysis, due to the extra time constraints this would have placed on busy participants (Birt et al. 2016). However, a sample of anonymised data was checked by the supervisory team in each phase to ensure that data and findings reported were consistent, thereby enhancing trustworthiness and credibility (Dawson, 2009; Noble and Smith, 2015). Moreover, verbatim quotations from participants were presented throughout Chapters Five, Six and Seven to illustrate and support the findings, thereby allowing readers to assess the consistency between the data presented and the accuracy of interpretations made (Tong, Sainsbury and Craig, 2007).

As recommended in the CREDES guidelines (Jünger et al. 2017), the study findings were discussed (Chapter Eight) and provide a consensus view from young carers and professionals on the areas that can present the most challenges to young carers aged 11-18 of a family member with a long term or progressive illness or disability. Access to the study's findings were enhanced through dissemination to relevant researchers, and also professionals and organisations that work with young carers. As documented earlier in this thesis, several poster and oral presentations were given about the study at various postgraduate conferences at two universities and at a university Faculty 'work in progress' session. Additional dissemination occurred through providing regular progress and summary reports to organisations and interested parties involved in the study. Further opportunities to disseminate findings through publication and at an international conference in 2020 are currently in development.

9.4 Limitations of the Study

As noted in the previous section, transcripts and findings were not returned to participants for validation during the first and final phases of the study. If they had been, comments and feedback could have enhanced the findings by allowing participants the opportunity to assess the accuracy of the researcher's recording and interpretations. This was initially considered, but was decided against due to the extra time and commitment required from young people and professionals who are already very busy (Birt et al. 2016). However, the role of the supervisory team in checking transcripts and findings to provide peer validation helped counterbalance this limitation. Additionally, due to the iterative nature of the study, findings from each phase were verbally reported to participants prior to the commencement of the next phase, giving participants the opportunity to comment on or discuss them at key stages in the process.

It is important to acknowledge that the sample size in this study was relatively small (n=251 for the Delphi study; n=10 for the pilot evaluation) and this could create limitations regarding generalisability and transferability of findings to all young carers aged 11-18, of a family member with a progressive or long-term illness or disability. Additionally, despite actively targeting health care professionals during the recruitment of participants in phase two of the study, it is disappointing to note that so few contributed to the survey. A greater level of participation by these professionals may have resulted in different items reaching consensus during analysis. However, their lack of engagement with the study may have been due to health professionals not seeing themselves as having such a key role in identifying or supporting young carers as the other professionals' groups who participated. Nevertheless, the data collected overall provided important insights into the experiences of young carers that have implications for practice and future research. The findings also confirmed those reported in existing literature. In terms of tool development, it can be argued that the sample size did not affect the overall development of the CAT-YC, as the survey items were generated from both the study's findings and the wider literature.

Study participants in the first and third phases were all from the North West of England and reported their ethnicity as White British. It may be that challenges related to caring activities,

and any resultant impact, are perceived differently according to ethnicity. A more ethnically diverse sample of participants may have resulted in different or additional items for consideration to include in the Delphi survey. The implications of this may limit the transferability or generalisability of the findings due to potential cultural or economic differences (Hunt and Lathlean, 2015). This is an area that would benefit from further research with a larger, more culturally diverse sample. However, the five different boroughs or regions within this area were diverse in respect of deprivation and affluence. Moreover, in phase two, findings indicated that young carer participants were represented not just from the North West of England but also from the North East, Yorkshire, West Midlands, South East, South West and Scotland. Similarly, professional participants were from every region in England, and from Wales, Scotland, Ireland, Canada and the USA. The findings were also strengthened by including representatives from national organisations within the expert panel during the final fourth round of the Delphi survey. Additionally, 25% (n=7) of young carer participants in round two of the Delphi survey and 24% (n=7) in round three, reported their ethnicity not to be White British. This, together with concordance of the findings with international literature, strengthens the findings and increases their transferability and relevance to wider audiences.

9.4 Original Contribution to Knowledge

As discussed in Chapter Eight, there is a lack of a short screening tool that can be used to identify unmet needs experienced by young carers, and triage them for support, advice or referral for a full statutory assessment of needs under either Section 96 of the Children and Families Act (2014), or Section 17 the Children Act (1989). None of the tools in the studies reviewed in Chapter Two were designed to both identify and screen for unmet needs in young carers aged 11-18, of a family member with a progressive or long-term illness or disability. Furthermore, none were developed using a consensus approach, as in this study. The development of the CAT-YC addresses this gap, and additionally includes items not included in other screening tools, such as making a plan of who to contact in case of an emergency. The involvement of young carers throughout every phase of this study has added an important contribution to the field. This study, therefore, provides a much-needed original

contribution to existing knowledge regarding collaborating with young carers when selecting current and relevant items during tool development.

Furthermore, the study has contributed significantly to methodological knowledge. The modified approach of using additional small consensus group meetings to collect the Delphi survey data ensured that young carers under 16 were able to fully participate, which has not been reported in other research. Moreover, as noted in Chapter Eight, most published research about young carers has involved participants who are from dedicated young carers' centres (Kennan, Fives and Canavan, 2012; Joseph et al. 2019). However, by including young carers who were not part of a dedicated young carers' centre in the first phase of this study, new findings emerged about the impact on a young carer's emotional wellbeing from having paid carers in the family home, as noted in Chapter Five. This has not been reported in other literature and suggests that support provided by paid carers may not necessarily be welcomed by all young carers. This important finding will lead to further research in the future.

Finally, the findings across the three phases of this study have highlighted some of the current shortfalls in practice, particularly relating to the undertaking of statutory assessments. The findings, therefore, add important and significant knowledge to the existing literature about the challenges that young carers continue to experience in the UK, despite changes to legislation.

9.5 Recommendations for Future Policy, Research and Practice

Based on the findings in this study, this section builds on the implications discussed in the previous chapter and provides recommendations for future policy, research and practice. Each of these areas are considered separately before the thesis concludes with some final words.

9.5.1 Future Policy

Policy development relating to young carers in the UK over the last ten years has mainly occurred through published findings from local research studies and subsequent campaigning by supporting non-governmental organisations (Joseph et al. 2019). The findings from this

study will add to the evidence base and may contribute to further policy development. As reported in Chapter One, policy changes in UK legislation state that young carers have a right to an assessment of their own needs when providing care (Care Act, 2014; Children and Families Act, 2014). However, it was argued that legislation is often confusing about which statutory bodies are responsible for undertaking assessments (ADASS, 2015; Leu and Becker, 2017). It is also unclear in the accompanying legislative guidance as to what may be deemed inappropriate or excessive tasks for young carers, when considering the care provided (Aldridge et al. 2016). Findings in this study support these arguments and also indicate that assessments are still inconsistently applied, with many young carers facing excessive delays in having their needs assessed. Without appropriate and timely interventions, young carers are likely to continue undertaking tasks that may impact their own health and wellbeing.

Based on the findings in this study, two recommendations are made for policy makers to consider. The first is for the provision of greater clarification in the guidance about the statutory duties of professionals who work with young carers. This is particularly important for those staff who may not consider young carers as part of their professional remit, so that they are clear about their role and responsibilities in supporting young carers. The second recommendation is that the legal right for a young carer to have an assessment of their own needs could be promoted more actively and widely, to help raise awareness and increase accountability.

9.5.2 Future Research

Based on the study limitations referred to earlier, several recommendations are made for future research. The first is for a longitudinal pilot study of the CAT-YC to be undertaken, with a larger more culturally diverse population of young carers. The purpose of this would be to establish face validity, and the CAT-YC's efficacy at identifying needs and the provision of support to reduce levels of need. Additionally, it could be piloted in different settings and by different professionals who support young carers. Once validity has been established, the second recommendation is for the CAT-YC to be used to explore the reported correlation between young carers who have a medical condition or learning disability themselves, and their role as a young carer (The Children's Society, 2013).

The third recommendation is for the CAT-YC to be used to allow comparisons to be made between young people who provide care for an ill or disabled family member, and those who live in a household where there is illness or disability, but the young person does not undertake a caring role. Finally, due to the limited amount of literature published about young carers who are not part of a dedicated young carers service, a fourth recommendation is that the CAT-YC also be used in schools to explore the prevalence of unidentified young carers. This information could be used to conduct further research that may in turn aid understanding of why some young carers continue to remain hidden in society.

9.5.3 Future Practice

In terms of recommendations for future practice, the focus for professionals working with young carers needs to be on prevention, assistance and mitigation, respectively, so that young people are not required to provide care. It was evident from the findings in this study that despite changes to legislation, young carers are often still not receiving statutory assessments. Findings indicated a lack of young carer awareness amongst some professionals, particularly from G.Ps, school nurses, teachers and professionals who are supporting a parent. The first recommendation therefore, is to include more training with these groups, in order to raise awareness and identification. This could extend to the CAT-YC being used to identify and screen young carers by other professionals, such as keyworkers in drug and alcohol support services, or Child and Adolescent Mental Health Services (CAMHS).

It was evident from the findings in this study and wider literature that even when young carers have been identified, they sometimes fall through the gaps of support provision. The second recommendation proposed is that once a young carer has been identified, professionals take a whole family approach to support, and communicate more clearly with other members of the team supporting the ill or disabled family member. A third recommendation is to include using information that has been recorded on the CAT-YC for evaluation purposes, to help identify which interventions have been most or least effective. This will help organisations plan and target their resources effectively.

9.6 Summary and Final Words

This chapter started by outlining the criteria used to evaluate the quality of how the study was conducted. Strengths and limitations were considered before a summary was given of how the key findings have made an original contribution to knowledge. Finally, a number of recommendations were proposed for future research, policy and practice.

This thesis demonstrates how an issue was identified, the lack of a suitable screening tool for use with young carers aged 11-18 of a family member with a long-term or progressive illness or disability, and a solution was developed that aims to make a difference to young carers' lives. Personal reflections of the study process are included as a post-script in Appendix 22; however, the final words really belong to Noah, one of the young carer participants who took part in each phase of the study:

> *'You have to actually listen to them [young carers] and acknowledge them! This is what you have to say!'*

It is envisaged that the CAT-YC has the potential to a give a voice to more young carers like Noah, thereby facilitating support and making a difference to their lives.

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Appendix 1: Extract from Reflective Journal

10/12/16

Went to visit a young carer aged 13 today, to conduct an interview in her home. The first thing that struck me as I went in was how little space there was. Her sister has multiple complex health issues and the lounge had been made into a bedroom for her. There was also a wet-room attached, leaving only a small kitchen/diner downstairs. The hall had an electric wheelchair in it, as well as a lightweight one. After a brief chat with her mum, I went through the purpose of the interview again and she signed an assent form while I set up my recorder.

The interview went well and she told me lots about how being a young carer affected her friendships and opportunities to go out. I was just packing up to leave when the doorbell went. 'Oh that will be one of the carers' she said. This seemed to trigger something else she wanted to tell me about being a young carer and she asked if she could say something else that was important. I got the recorder out again and asked her what it was. She told me how annoying it was having so many strangers in the house. Her sister needed care 24 hours a day, so carers from an agency came on a rota. She said that once she came down in the night for a drink and there was a man she didn't know in the kitchen, getting a drink himself. Often when she came in from school, a carer would be at the kitchen table while her mum was with her sister. She felt she couldn't 'be herself' with all these different people coming and going. But when her sister was in hospital everything changed; the carers stopped coming, her mum stayed with her sister and the house would be really quiet. She said she had more jobs to do then but at least she could be herself, have a friend around and not need to be quiet.

When I got home, I thought a lot about what she had said. I was surprised to realise I had made an assumption before seeing her that young carers must welcome support from others as it would relieve them of carrying out care themselves. I hadn't really thought about how their lives were affected regardless of what they did or didn't do. I reflected on where this had come from; had my role as a foster carer influenced my assumptions? Was I guilty of wanting to 'rescue' them from their role? Honestly, I don't know. Maybe. But importantly, having the opportunity to reflect meant that at least it was in my awareness now, and hopefully next time I will be able to bracket it off and stay open to what a participant tells me.

Appendix 2: Ethics Approval Letter 7/8/17

Edge Hill University

Lynn Kettell 7th August 2017

Dear Lynn,

Thank you for submitting your research ethics application '*Developing the Carers' Alert Thermometer (CAT) for use with young carers of family members with a progressive illness (CAT-YC)*' (FOHS 184) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principle Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

5. The Principle Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 31/08/2019. Any extensions to this date will require additional approval from the committee.

The study documentation that has been reviewed and approved is detailed below:

	<version no & date>
Proposal	**V2, 26/07/2017**
Phase 1 Assent for YCs 11-15	**V1, 20/06/2017**
Phase 1 Consent for YCs 16-18	**V2, 26/07/2017**
Phase 1 Focus Group Interview Schedule for Young Carers	**V1, 20/06/2017**
Phase 1 Information for Parents	**V1, 20/06/2017**
Phase 1 Interview Schedule	**V1, 20/06/2017**
Phase 1 Invitation and Information for Young People 16-18	**V2, 26/07/2017**
Phase 1 Invitation for YCs 11-15	**V1, 20/06/2017**
Phase 1 parent or Legal Guardian Consent form for UCs 11-15	**V2, 26/07/2017**
Phase 2 Assent Form for YCs 11-15	**V1, 20/06/2017**
Phase 2 Flyer for young carers 16-18	**V1, 20/06/2017**
Phase 2 Information for ParentsLegal Guardians	**V1, 20/06/2017**
Phase 2 Information for Professionals (Delphi)	**V1, 20/06/2017**
Phase 2 Invitation for YCs 11-15	**V1, 20/06/2017**
Phase 2 Parent_Legal Guardian Consent form for Young People to Participate	**V2, 26/07/2017**
Phase 2 PIS for Expert Panel (Professionals)	**V1, 20/06/2017**
Phase 2 PIS for Expert Panel (YCs)	**V1, 20/06/2017**
Phase 2 PIS for YCs Delphi 16-18	**V1, 20/06/2017**
Phase 2 Sample Email Invitation to Professional Members of the National Expert Panel	**V1, 20/06/2017**
Phase 2 Sample Email Invitation to Young Carer Members of the Expert Panel	**V1, 20/06/2017**
Phase 2 Standard Email Invitation for Professionals (Delphi)	**V1, 20/06/2017**
Phase 2, Sample Preface to Online Survey	**V1, 20/06/2017**
All Phases List of Support Organisations	**V1, 20/06/2017**

Yours sincerely

Dr Genevieve Stone

Acting Chair of Faculty of Health & Social Care Research Ethics Committee
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP

Appendix 2a: Ethics Approval Letter 26/2/19

Edge Hill University

Lynn Kettell

26th February 2019

Dear Lynn,

Thank you for submitting your research ethics application '*Evaluating the Pilot Study of the Carers' Alert Thermometer for Young Carers (CAT-YC)*' (FOHS 184) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. If required, an application must be made to the HRA for approval for the research to be conducted in the NHS. NHS R&D departments (in Trusts where data is being collected) may also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study. FREC approval is subject to the receipt of evidence of appropriate external approvals.

4. The Principal Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) / General Data Protection Regulation (GDPR) (2018) and as detailed within the approved proposal.

5. The Principal Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 06-09-2019. Any extensions to this date will require additional approval from the committee.

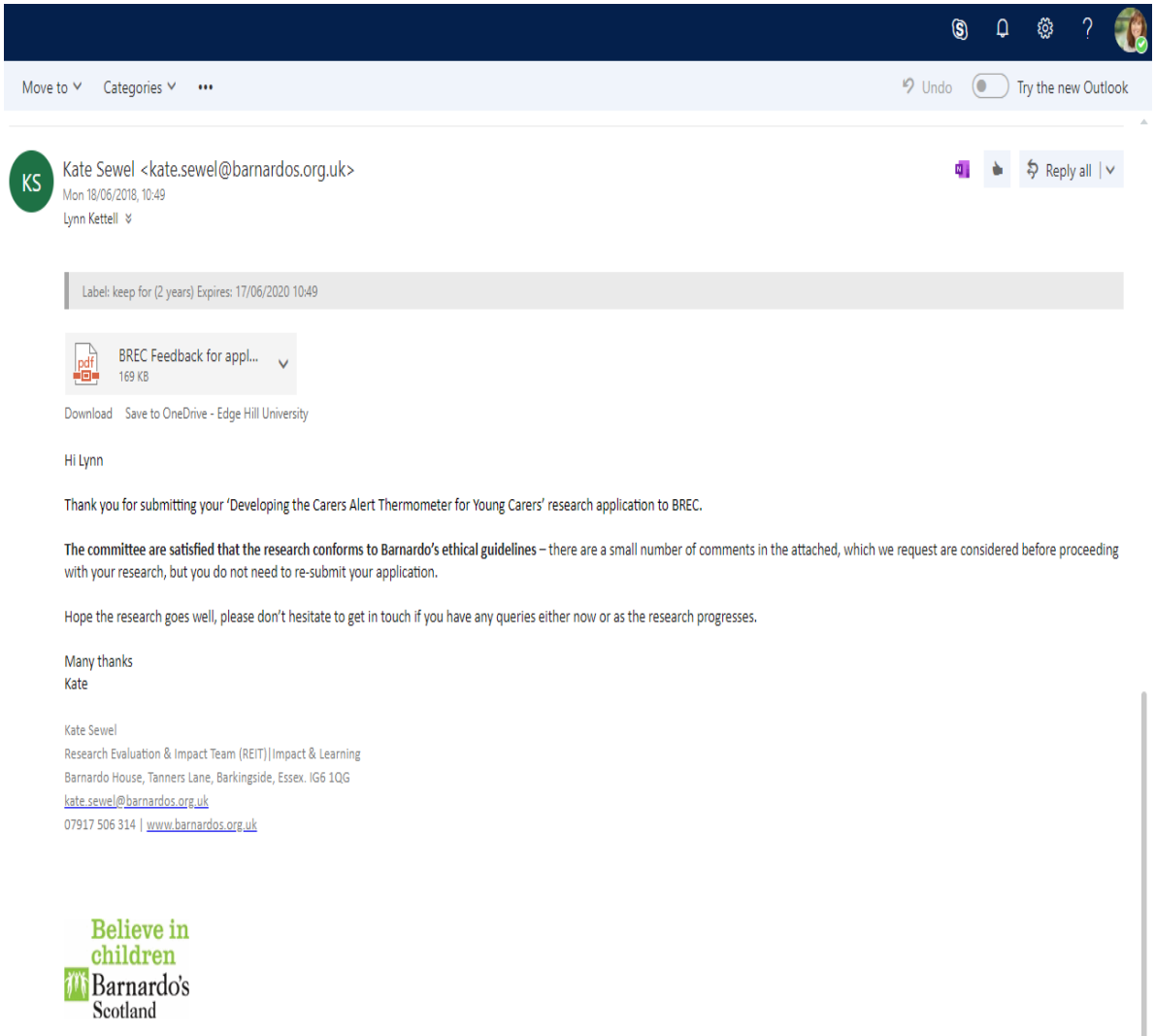
The study documentation that has been reviewed and approved is detailed below:<doc title>	**<version no & date>**
Faculty Research Proposal Form	**V2, 22-02-2019**
All Phases List of Support Organisation's	**V1, 05-02-2019**
Phase 3 Sample Email Invitation	**V2, 22-02-2019**
Phase 3 PIS Evaluation Invitation (Professionals)	**V2, 22-02-2019**
Phase 3 PIS for Parents or Legal Guardians	**V2, 22-02-2019**
Phase 3 Invitation and PIS for YCs 16-18	**V2, 22-02-2019**
Phase 3 Invitation and PIS for YCs 11-15	**V2, 22-02-2019**
Phase 3 Consent for Professionals	**V2, 22-02-2019**
Phase 3 Consent for YCs 16-18	**V2, 22-02-2019**
Phase 3 Assent Form for YCs 11-15	**V2, 22-02-2019**
Phase 3 Parent or Legal Guardian Consent for YCs 11-15	**V2, 22-02-2019**
Phase 3 Interview Schedule for Professionals	**V1, 05-02-2019**
Phase 3 Interview Schedule for YCs	**V2, 22-02-2019**

Yours sincerely

Dr Nicola Relph

Acting Chair of Faculty of Health & Social Care Research Ethics Committee
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP

Appendix 3: Ethics Approval Letter Barnardo's 18/6/18



Move to ⌄ Categories ⌄ ••• Undo Try the new Outlook

KS

Kate Sewel <kate.sewel@barnardos.org.uk>
Mon 18/06/2018, 10:49
Lynn Kettell ⌄

Reply all ⌄

Label: keep for (2 years) Expires: 17/06/2020 10:49

BREC Feedback for appl...
169 KB

Download Save to OneDrive - Edge Hill University

Hi Lynn

Thank you for submitting your 'Developing the Carers Alert Thermometer for Young Carers' research application to BREC.

The committee are satisfied that the research conforms to Barnardo's ethical guidelines – there are a small number of comments in the attached, which we request are considered before proceeding with your research, but you do not need to re-submit your application.

Hope the research goes well, please don't hesitate to get in touch if you have any queries either now or as the research progresses.

Many thanks
Kate

Kate Sewel
Research Evaluation & Impact Team (REIT)|Impact & Learning
Barnardo House, Tanners Lane, Barkingside, Essex. IG6 1QG
kate.sewel@barnardos.org.uk
07917 506 314 | www.barnardos.org.uk

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Appendix 4: **Phase 1 Focus Group Interview Schedule for Young Carers**

Edge Hill University

Focus Group for Young Carers: Semi-Structured Guide (Phase 1)

Introductions and Explanations:

- Remind young people who I am and what the study is about
- Introduce the observer and explain their role in the group
- Thank the young people for taking part
- Revisit information from assent/consent sheets, answer any questions and confirm ongoing assent/consent *(consent from parent/legal guardian will have been checked prior to meeting)*
- Explain that it is okay to take a break, not answer a question or leave the group if they want to
- Show them the audio-recorder and confirm their understanding of why I will be recording the meeting

(Spend a few minutes talking about general things to help them settle and feel more at ease. Give out sticky labels and ask them to write their name on one. Explain ground rules, e.g. confidentiality, turn-taking etc)

Demographic information about each participant will have been obtained from staff prior to the focus group meeting. This will include participants:

- Age/gender
- Family composition – who they live with; if they have siblings, position in family
- Who they help care for
- How long they have been a young carer
- Their family member's medical condition

Focus Group Questions:

(Place large sheet of paper and lots of coloured pens on table/floor in centre of group)

1. **Can you write down what words you would use to describe what being a young carer means to you, what words would you use?**
   (Prompts: if you were trying to explain to someone what a young carer is or does, what words would you say?)

   a. **Do you think other people would describe young carers in the same way?**
      (Prompts: family? Friends? Teachers?)(If different, explore more)

2. **Can you tell me what sorts of things you do as a young carer for the person in your family you help care for?**
   (Prompts: practical things, emotional support, day to day things)

   a. **How much time does this take?**
   (Prompts: daily/weekly - does this ever change?)

3. **How does being a young carer affect your life?**
   (Prompts: home? School? Friendships? Hobbies?)

   a. **How do you deal with these things?**
   (Prompts: practical ways? Help from others?)

4. **How do you feel about being a young carer?**
   (Prompts: Can you think of any words to describe how you feel?)

   a. **What are the good things about being a young carer?**
   (Prompts: anything you enjoy? Feel good about?)

   b. **And the not so good things?**
   (Prompts: anything you find difficult? Struggle with?)

5. **What things help you now in your caring role?**
   (Prompts: what makes a difference? Easier? Home/School/Young Carers' Group)

6. **Do many people know you are a young carer?**
   (Prompts: Friends? Teachers? If not, explore more)

7. **What things would help you more?**
   (Prompts: what would you like extra help with? At home? School?)

   Make clear I cannot provide these things

8. **Have any of you had a young carers' assessment?**
   (Prompts: someone asking you about your needs as a young carer?)

   a) (*If yes)* **When did you have this?**
   (Prompts: who did it? how long did you wait? Did anything change?)

9. **Is there anything else anyone wants to say?**
   (Prompts: anything important I might have missed? Anything you weren't sure of? Any last words before we finish?

Endings:

- Thank them for taking part
- Check each young person is okay (*provide support organisation details as required)*
- Spend a few minutes bringing the conversation back to general things – (e.g. what are you going to do now?)

Appendix 5: Phase 1 Consent Form for Young People 16-18

Edge Hill University

Developing the Carers' Alert Thermometer for Young Carers (CAT-YC)

Consent Form for Young People 16-18

Please initial the boxes

I confirm I have read and understand the CAT-YC-V2-26 July 2017, Invitation and Information Sheet for Young People 16-18, Phase 1 and have had the opportunity to ask any questions about this phase of the study.	
I understand that taking part is voluntary and I can change my mind about taking part before, during or up to seven days after an individual or telephone interview, without giving a reason.	
I understand that Lynn will digitally record the interview to help her remember what was said afterwards when she writes about her study but won't use my name or any details that could identify me. I agree for this to happen.	
I know Lynn will write about some of the things I say in her study and future documents or presentations that other people will read. I know that Lynn will not use my real name in this, so I cannot be identified.	
I know the things I say and that Lynn writes about may be looked at by people from Edge Hill University and other organisations to check she is doing the research properly.	
I agree to take part in this phase of the study.	

Name of Participant _____ Date _____ Signature _____

Name of Researcher _____ Date _____ Signature _____

Appendix 6: **Phase 2 Information for Parents/Legal Guardians**

Edge Hill University

Developing the Carers' Alert Thermometer for Young Carers (CAT-YC) Phase 2 (Small Group Meetings)

Information for Parents/Legal Guardians

Thank you for reading this information sheet. My name is Lynn Kettell and I am a PhD student at Edge Hill University. Your child has been invited to take part in a project about young carers.

Before you decide whether you agree to them taking part or not, it is important for you to understand why this study is being done and what it will involve. Please take your time to read the following information and if anything is not clear, please feel free to contact me or my supervisor using the contact details at the end of the sheet

What is the aim of this project?

The aim is to develop a short screening form called the CAT-YC, containing no more than ten questions asking young carers about any needs they may have, or support they require. This will act as a triage tool to identify young carers who need to have a full young carers' assessment, or support that would help them in their caring role. The project has several phases. This phase will involve asking young carers and professionals to decide on the questions to include in the CAT-YC based on information provided by young carers in an earlier interview phase.

Why has my child been asked to take part?

Your child has been asked to take part as they attend a young carers' centre and will therefore have experience of helping look after a family member who has a long term illness or disability. They may have taken part in an earlier interview phase of the project, but it does not matter if they haven't as I need more young carers to take part in this phase.

What will happen if my child wants to take part and I agree?

For this part of the project, I will arrange a small group meeting at a young carers' centre, with about 6-10 young carers there. Each young person will be given the same list of questions in a survey and asked to choose the ones they feel are the most important to include in the CAT-YC. This activity will take no more than 45 minutes to complete. I will be asking young carers from other centres and people who work with young carers to complete the survey too. When I analyse the results from all the surveys, if there are too many for the CAT-YC form, I will come back to the centre again about 6-8 weeks later with a shorter survey of the most popular questions chosen. Your child will be asked if they want to take part again.

Does my child have to take part?

No, it is entirely up to them and you to decide whether they want to participate. If they want to take part, you will be given or sent a consent form which must be returned to me before they can participate. If you consent to them taking part in the first meeting, it will be assumed that you consent to them taking part a second time, unless you tell me that they are not to be invited.

Will anyone else know that they are taking part?

The other people at the group meeting will know they have taken part, although the individual surveys themselves will not have names or identifying details on them.

What are the possible benefits of taking part?

I hope they will enjoy taking part. I hope the CAT-YC form containing the chosen questions and suggestions will help people who work with young carers understand more about what they do, so that the right support can be given quickly and easily.

What are the possible disadvantages of taking part?

I don't think there are any disadvantages to taking part. Your child might feel upset reading some of the questions in the survey. If this happens, they can skip the question(s) or stop taking part. I will give you and your child details of support organisations you/they can contact if further support is needed.

What will happen to the results of the study?

The top questions from the survey(s) will be used to make the CAT-YC, which will then be tested in a later phase. I hope the final form will be used by relevant professionals who work with young carers. The results from the study will be written about in my thesis and may be published in academic journals or presented at conferences, but no details will be given that could identify your child.

Who has reviewed the study?

The Faculty of Health and Social Care Research Ethics Committee at Edge Hill University has reviewed and approved the study.

What if I have some questions?

You can contact me directly, if you have any questions at all. My phone number is **01695 654 353** or email is Kettelll@edgehill.ac.uk

What if I am not happy about this study?

If there is anything in the study you are not happy about, you can contact Dr Katherine Knighting, who is my director of studies at Edge Hill University, on 01695 657 170, or email Knightk@edgehill.ac.uk. If you want to speak to someone outside the research team, you can contact Professor Clare Austin, Associate Dean of Research & Innovation on 01695 650772, or austincl@edgehill.ac.uk

Thank you for reading this information and for considering your child's participation in this study

Appendix 7: **Phase 2 Flyer for young carers 16-18**

Edge Hill University

Are you a young carer aged 16-18?

Do you help support a family member who has a long term illness or disability?

Would you like to have your say about support for young carers?

Researchers at Edge Hill University would like to know your views on what support does or could make a difference for young carers like yourself at home, school/college, or in life generally.

Please take part in a 20 minute survey to develop a new screening form to help young carers get the right support at the right time. Further information about the study is available on the website below:

https://www.surveymonkey.co.uk/r/CAT-YC16-18

The closing date for the survey is **25 July 2018**

If you have any questions about the study, please contact the principal researcher Lynn Kettell on:

01695 654 353 (Monday-Friday 9am-5pm)

kettelll@edgehill.ac.uk

Appendix 8: **Phase 3 PIS Evaluation Invitation (Professionals)**

Edge Hill University

Developing the Carers' Alert Thermometer for Young Carers (CAT-YC) Phase 3

Participant Information Sheet for Professionals

(Evaluation Interviews)

Researcher: Lynn Kettell

Supervisory Team:
Dr Katherine Knighting, Professor Barbara Jack, Professor Mary O'Brien

Background to the study

In 2014, with funding from the NIHR, researchers from Edge Hill University developed the Carers' Alert Thermometer (CAT) – a short screening tool to identify and support the needs of carers caring for a family member with an advanced or progressive illness. It contains 11 questions aimed at identifying carer needs, along with a scoring system and suggested next steps section for any alerts identified.
The CAT has subsequently been adapted and successfully used with adult carers of people with a range of health issues including stroke, cancer and motor neurone disease. Further details about the CAT can be found at www.edgehill.ac.uk/carers

However, the CAT was developed for use with adult carers so needs to be adapted for use with young carers, as it would need to contain different questions along with a different next steps section. Therefore, following similar consensus based principles, a new Carers' Alert Thermometer for Young Carers (CAT-YC) is being developed as part of my PhD project. The project has been reviewed and approved by the Faculty of Health and Social Care Research Ethics Committee at Edge Hill University.

What does the project involve and who are the participants?

The project involves several phases. The first phase gathered the views and experiences of a range of young carers aged 11-18 in the North West of England who provide care for a family member with a progressive illness, through individual interviews and focus groups.

Following analysis of the findings from the first phase, a Delphi survey was sent out online or given to a larger number of young carers and professionals in phase two, to reach consensus on the most important items to include in the CAT-YC. This was then reviewed by an expert panel comprising of key professionals with a strategic role in young carer support and young carers who participated in earlier phases. Following their review, a pilot version of the CAT-YC has been developed. Your organisation has agreed to trial the pilot version of the CAT-YC for usability.

How you can help

The purpose of this phase of the study will be evaluate the findings from the trial and find out if any modifications or refinements are necessary before the CAT-YC is trialled in a larger pilot study. If you want to participate in this phase, you will be asked to take part in a short interview about your experience of completing the pilot version of the CAT-YC. The interviews will be digitally recorded and should take no more than 30 minutes, arranged at a time that is convenient for you. You will also be asked to give all the young carers you have completed the CAT-YC with an information pack to take home, inviting them to take part in an interview. The CAT-YC form will be retained by your organisation in accordance with their own data storage policies, and I do not need access to the individual forms.

What will happen with the results?

The anonymised results of the project will be written up in my thesis and may be published in academic journals, or presented at conferences and on the CAT website mentioned earlier.

Who can I contact if I have any questions or concerns about the study?

In the first instance please contact Lynn Kettell on **01695 654 353** or at kettell@edgehill.ac.uk Alternatively you can contact my director of studies at Edge Hill University, Dr Katherine Knighting, on **01695 657 170** or at knight@edgehill.ac.uk
If you prefer to speak to someone outside the research team, you can contact Professor Clare Austin, Associate Dean of Research and Innovation on **01695 650 772** or at austincl@edgehill.ac.uk

Thank you for your time reading this information

Appendix 9: **Phase 3 Invitation and PIS for YCs 16-18**

Edge Hill University

Developing the Carers' Alert Thermometer for Young Carers (CAT-YC)

Phase 3

Invitation and Information for Young People 16-18

(Pilot Evaluation Interview)

Hi, my name is Lynn and I am a PhD student at Edge Hill University. I would like to ask you to take part in the final phase of a project about young carers' needs.

Before you decide whether to take part it is important for you to understand what the project is about and what it will involve.

What is the aim of this project?

The aim is to develop a short screening form called the CAT-YC, with the most important 10 questions people working with young carers should ask. The CAT-YC form will also have suggestions for what needs to happen after the form has been completed that would be helpful for young people like yourself.

Why have I been asked to take part?

You have been asked because you know best what it is like to help look after someone in your family who needs support. You may already have taken part in earlier phases of the project, but If you didn't take part then, you can still take part in this phase. A member of staff at the young carers' centre will have completed a CAT-YC form with you and I would like to know how you found this experience.

What will happen if I want to take part?

For this part of the project, I would like to ask you some questions about completing the form, for instance how long it took, and whether the questions were easy or difficult to understand. This will take no more than 30 minutes and I can speak to you at the centre or at your home, whichever you prefer.

Will anyone else know that I am taking part?

The staff member who filled in the CAT-YC form with you will know, but nobody else will know unless you choose to tell them. I will digitally record our meeting to help me write my notes afterwards, but I won't use your name in anything I write.

The results of the study will be written about in my work and in academic publications, but no details will be used that can identify anyone who takes part

Do I have to take part?

No. It is your choice whether you want to take part and nobody will mind if you don't want to. You can also change your mind about taking part before or while you are talking to me, or up to seven days afterwards.

What are the good things about taking part?

I hope you will enjoy taking part. I hope the answers you give will help me make the CAT- YC as useful as it can be, so that better support and information can be given to all young carers in the future.

What are the bad things about taking part?

I don't think there is anything bad about taking part, but you might feel upset talking about the questions on the form. I will give you details of some support organisations you can contact if you feel you need support.

Did anyone else check the study is okay to do?

Yes. Before a study like this can start, an ethics committee from Edge Hill University meet and read everything, to make sure it is okay to do.

What if I have some questions?

You can ask a staff member at the centre to contact me, or you can phone or email me yourself. My phone number is **01695 654 353** or my email is Kettelll@edgehill.ac.uk

What if I am not happy about this study?

If there is anything in the study you are not happy about, you (or someone on your behalf) can contact Dr Katherine Knighting, who is my director of studies at Edge Hill University, on 01695 657 170, or email Knightk@edgehill.ac.uk. If you/they want to speak to someone outside the research team, they can contact Professor Clare Austin, Associate Dean of Research & Innovation on 01695 650772, or austincl@edgehill.ac.uk

Thank you for reading this and thinking about my study!

Please keep this information sheet

Appendix 10: R2 Delphi Survey Topics and Items

(TOPIC 1) How important is it to ask the young person...	
1	...how long they have been caring for someone in their family?
2	...how much time they spend on average caring each day/week?
3	...if they have support from another adult in the home?
4	...if they need support to continue their caring role?
5	...if they need practical support or training to help them provide care?
6	...if they need support with financial matters, e.g. benefits, housing?
7	...if they want or need information about their family member's condition/disability?
8	...if they feel included in support decisions about their family member?
9	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?
(TOPIC 2) How important is it to ask the young person...	
1	...about the type of things they do to help in their caring role?
2	...if they are providing emotional support, e.g. keeping company or comforting?
3	...if they are helping with personal care, e.g. washing, dressing?
4	...if they are helping with practical household tasks, e.g. cleaning, laundry?
5	...if they are providing physical support, e.g. lifting, moving?
6	...if they are giving medication to the person they care for, or checking it has been taken?
7	...if they are attending appointments with the person they care for?
8	...if they are looking after siblings?
9	...if they are undertaking tasks they don't want to do?
(TOPIC 3) How important is it to ask the young person...	
1	...if they need support with their physical health?
2	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?
3	...if they have a friend or family member they can speak to or contact for help or support?
4	...if they spend time with their friends?
5	...if they spend time with their family members?
6	...if they want a break or time away from their caring role?
7	...if they attend/receive support from a young carers' service?
8	...if they need help accessing a group, or any other clubs in their schools or local community?

(TOPIC 4) How important is it to ask the young person...	
1	...whether they see themselves as a young carer?
2	...if they feel recognised and supported by others for their caring role?
3	...if they feel bullied or stigmatised by others for their caring role?
4	...if they want or need support speaking to people about their caring role?
5	...if they have someone who can speak on their behalf, if necessary?
(TOPIC 5) How important is it to ask the young person...	
1	...if there is a named staff member at their school/college for young carers?
2	...if they want or need help to make staff at school/college aware of their caring role?
3	...if there are specific needs they have in school/college, e.g. extra time for homework?
4	...if there is anything that could help reduce stress/anxiety at or about school/college?
5	...if they need additional advice/support about future education or career options?
6	...if they intend to continue in their caring role after leaving school/college?

Appendix 11: Delphi Survey R2

Edge Hill University

Survey of Priorities for a Carers' Alert Thermometer for Young Carers (CAT-YC)

WELCOME TO THE SURVEY

As someone who understands the challenges young carers sometimes face, your help in this study is greatly appreciated. Before you decide whether to take part, please read the information sheet (accessed through the flyer) which contains more information about the study and what it involves. Participation is voluntary, and you can answer all of the questions or just the ones you are comfortable with. Completion of the survey indicates your consent to take part and should take no more than 20 minutes to complete. The survey needs to be completed in one go as it is not possible to save answers and come back to it later.

The items in the survey are based on what has been shared by young carers in other research and reports, and by 26 young carers aged 11-18 in recent interviews and a focus group. All of their views are important, but for the CAT-YC to be useful, it cannot be too long. I therefore need your help, so I can understand what the '*most*' important items are to include in the CAT-YC.

Instructions for completing the survey

The survey has three sections and all of your responses will be confidential. Section A collects anonymous information about the person completing the survey. Section B invites you to rate items from 1 '*not at all important*' to 5 '*extremely important'* from a list of 5 topics according to how important you think that item is for inclusion on the CAT-YC. For example:

Topic 1: Understanding the caring situation

How important is it to ask the young person...	***not at all important***	***not very important***	***important***	***very important***	***extremely important***
1) ...how long they have been caring for someone in their family?	1	2	**3**	4	5
2) ...if they have support from another adult in the home?	1	2	3	**4**	5

Section C invites you to give your views on the development and future use of the CAT-YC.

SECTION A: YOUR DETAILS

All responses to this survey will remain anonymous, as I will not ask for your name or any personal details, but the following questions will help me know something about the person completing the survey, in terms of your experience as a young carer.

1) Please select whether you are a young carer aged:

☐ 16 ☐ 17 ☐ 18

2) Are you...?

☐ Male ☐ Female ☐ Prefer to self-identify ☐ Prefer not to say

3) Which ethnicity do you identify with?

☐ White	☐ Asian or Asian British	☐ Chinese	☐ Don't know
☐ Mixed/multiple ethnic group	☐ Black or Black British	☐ Other ethnic group	☐ Prefer not to say

4) What town do you live in? .....

5) Who do you <u>mainly</u> help care for?

☐ Mother	☐ Step-Mother	☐ Younger sibling	☐ Grandparent
☐ Father	☐ Step-Father	☐ Older sibling	☐ Other.....

6) Does the person you (mainly) care for have a...? (Please select all that apply)

☐ Physical health condition	☐ Mental health condition	☐ Alcohol/drug issue	☐ Don't know
☐ Physical disability	☐ Sight or hearing loss	☐ Learning difficulty	☐ Prefer not to say
More information:			

7) Do you help care for anyone else?

☐ Yes ☐ No

[If yes is selected, questions 5 and 6 are repeated. If no is selected it will go straight to question 8]

8) How long have you been caring for...?

☐ less than 1 year ☐ 1-2 years ☐ 3-5 years ☐ 6-8 years ☐ 9 years or more

9) Thinking about an <u>average</u> week, how many hours would you say you spend helping or looking after the person (or people) you care for?

☐ Less than 10	☐ 11-20	☐ 21-30	☐ 31-40	☐ More than 41

SECTION B: TOPICS FOR THE CAT-YC

In this Section, the survey items are listed under 5 topics. Thinking about the care provided by young carers and their own health and social wellbeing, for EACH of the items please select ONE number on the scale to indicate **how important you think that item is for inclusion on the CAT-YC,** with 1 being *'not at all important'*, 3 being '*important'* and 5 being *'extremely important'.*

Topic 1: Understanding the caring situation

How important is it to ask the young person...	***not at all important***	***not very important***	***important***	***very important***	***extremely important***
1) ...how long they have been caring for someone in their family?	1	2	3	4	5
2) ...how much time they spend on average caring each day/week?	1	2	3	4	5
3) ...if they have support from another adult in the home?	1	2	3	4	5
3) ...if they need support to continue in their caring role?	1	2	3	4	5
4) ...if there is practical support or training that could help them?	1	2	3	4	5
5) ...if they want or need information about their family member's condition or disability?	1	2	3	4	5
6) ... if they have a plan of who to contact in case of an emergency?	1	2	3	4	5
Any Comments on Topic 1?					

Topic 2: Details of the care provided by the young person

How important is it to ask the young person...	***not at all important***	***not very important***	***important***	***very important***	***extremely important***
7) ...about the type of things they do to help the person in their caring role?	1	2	3	4	5
8) ...if they are providing emotional support, e.g. comforting?	1	2	3	4	5
9) ...if they are helping with personal care, e.g. washing, dressing?	1	2	3	4	5
10) ...if they are helping with practical tasks, e.g. cleaning, laundry?	1	2	3	4	5
11) ...if they are providing physical support, e.g. lifting, moving?	1	2	3	4	5
12) ...if they are giving medication to the person they care for?	1	2	3	4	5
13) ...if they need support with financial matters?	1	2	3	4	5
14) ...if they need support organising or managing appointments for their family member?	1	2	3	4	5
Any Comments on Topic 2?					

Topic 3: The young carer's health and social wellbeing

How important is it to ask the young person...	*not at all important*	*not very important*	*important*	*very important*	*extremely important*
18) ...if they need support with their physical health?	1	2	3	4	5
19) ...if they need support with their emotional wellbeing, e.g. counselling?	1	2	3	4	5
20) ...if they need support or advice about coping strategies?	1	2	3	4	5
21) ...if they have someone they can speak to or contact for help or support?	1	2	3	4	5
22) ...if they spend time with their friends and/or other family members?	1	2	3	4	5
23) ...if they want a break or time away from their caring role?	1	2	3	4	5
24) ...if they attend a young carers' group?	1	2	3	4	5
25) ...if they need help accessing a group, or any other clubs?	1	2	3	4	5
Any Comments on Topic 3?					

Topic 4: The young carer's identity and self-esteem

How important is it to ask the young person...	*not at all important*	*not very important*	*important*	*very important*	*extremely important*
26) ...if they are comfortable with the term 'young carer'?	1	2	3	4	5
27) ...if they feel recognised and supported by others for their caring role?	1	2	3	4	5
28) ...if they feel included in support decisions about their family member?	1	2	3	4	5
29) ...if they feel bullied or stigmatised by others for their caring role?	1	2	3	4	5
30) ...if they want or need support speaking to people about their caring role?	1	2	3	4	5
31) ...if they are undertaking tasks they don't want to do?	1	2	3	4	5
32) ...if they have someone who can speak on their behalf, if necessary?	1	2	3	4	5
33) ...if they need help accessing services that could help them?	1	2	3	4	5
Any Comments on Topic 4?					

Topic 5: Education and future plans

How important is it to ask the young person...	*not at all important*	*not very important*	*important*	*very important*	*extremely important*
34) ...if there are specific needs they have in school/college, e.g. extra time for homework?	1	2	3	4	5
35) ...if there is anything that could help reduce stress/anxiety at or about school/college?	1	2	3	4	5
36) ...if there is a named staff member at their school/college for young carers?	1	2	3	4	5
37) ...if they want or need help to make staff at school/college aware of their caring role?	1	2	3	4	5
38) ...if they need additional advice/support about future education or career options?	1	2	3	4	5
39) ...if they want to continue in their caring role?	1	2	3	4	5
Any Comments on Topic 5?					

SECTION C: YOUR VIEWS ON THE DEVELOPMENT AND FUTURE USE OF THE CAT-YC

1) How important do you think it is for young carers to have <u>their</u> needs assessed?

not at all important	*not very important*	*important*	*very important*	*extremely important*
1	2	3	4	5

2) As situations can change over time, how often do you think young carers' needs should be reviewed <u>as a minimum?</u>

☐ Monthly ☐ Every 3 months ☐ Every 6 months ☐ Every year

3) Who do you think would be best suited to use the CAT-YC with young carers?
(please tick as many as you think may apply, but please remember that the person conducting the CAT-YC must be able to take action on any needs identified, whether this is personally, by making a referral, or contacting an appropriate person or service).

☐ Carer centre staff	☐ Teachers	☐ Other school staff	☐ School nurse
☐ GP	☐ Practice Nurse	☐ Social worker	☐ Anyone who has contact with young carers
☐ Other....			

4) Your preferences of Topics for the CAT-YC
Listed below are the 5 main topics which are included in this survey. All of them are important but I would like you to indicate your preference of topics to be included in the CAT-YC by ranking them from 1st to 5th place. For example, select '1' in the box next to the topic you think is the most important, '2' for the second most important, and so on until you have ranked all 5 topics, from 1st to 5th place. Each topic must be ranked in a different place so <u>please do not use the same number twice.</u>

TOPIC 1: Understanding the caring situation	
TOPIC 2: Details of the care provided by the young person	
TOPIC 3: The young carer's health and social wellbeing	
TOPIC 4: The young carer's identity and self-esteem	
TOPIC 5: Education and future plans	

5) Do you have any additional comments you would like to make...?

Appendix 12: R2 Responses to Topics 1-5 (Full Table) Round Two

Participants from both cohorts rated 37 items across 5 main topics on a 5 point Likert scale, with (1) being *'not at all important'*, (3) being '*important'* and (5) being '*extremely important'*. The table below presents the sample, mean and standard deviation, median and interquartile range (IQR), and consensus level for each item. SDS>1 are in bold to highlight items with more spread in their ratings.

Criterion for accepting an item: at least 60% of both the young carer and professional cohorts rated an item as (4) '*important'* or (5) '*extremely important* (noted as MET)

Criterion for re-rating an item: if 60% of one cohort rated an item as (4) '*important'* or (5) '*extremely important*' but the other cohort did not, suggesting disagreement between the cohorts (noted as QUERY)

Criterion for rejecting an item: any items that did not meet the 60% criteria in both cohorts (noted as REMOVE)

Table 26: Round 2 Full Table Topic 1

TOPIC 1: UNDERSTANDING THE CARING SITUATION **How important is it to ask the young person...**		**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
1	...how long they have been caring for someone in their family?	96	3.70 (.92)	4 (1.00)	56%	68	3.86 (.91)	4 (2.00)	66.2%	28	3.27 (.83)	3 (1.00)	32.1%	QUERY
2	...how much time they spend on average caring each day/week?	95	3.84 (.96)	4 (1.00)	60%	67	4.03 (.94)	4 (2.00)	70.2%	28	3.32 (.84)	3 (1.00)	35.7%	QUERY
3	...if they have support from another adult in the home?	94	4.34 (.75)	4 (1.00)	84.1%	66	4.52 (.63)	5 (1.00)	92.4%	28	3.86 (.83)	4 (1.25)	64.3%	MET
4	...if they need support to continue their caring role?	94	4.33 (.90)	5 (1.00)	81.9%	66	4.59 (.62)	5 (1.00)	94%	28	3.64 (**1.13**)	4 (2.00)	53.6%	QUERY

TOPIC 1: UNDERSTANDING THE CARING SITUATION **How important is it to ask the young person...**		**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
5	...if they need practical support or training to help them provide care?	94	3.94 (**1.04**)	4 (2.00)	66%	67	4.16 (.95)	4 (1.25)	76.2%	27	3.36 (**1.05**)	3 (1.00)	40.7%	QUERY
6	...if they need support with financial matters, e.g. benefits, housing?	94	4.11 (**1.01**)	4 (1.75)	72.4%	67	4.19 (.83)	4 (2.00)	74.6%	27	3.91 (**1.38**)	5 (2.00)	66.6%	MET
7	...if they want or need information about their family member's condition/disability?	95	3.86 (.90)	4 (2.00)	64.2%	67	3.95 (.83)	4 (2.00)	71.7%	28	3.64 (**1.05**)	3 (2.00)	46.4%	QUERY
8	...if they feel included in support decisions about their family member?	95	4.00 (.83)	4 (2.00)	70.5%	67	4.09 (.76)	4 (1.25)	97%	28	3.77 (.97)	4 (2.00)	57.1%	QUERY
9	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	95	4.56 (.69)	5 (1.00)	90.6%	67	4.69 (.50)	5 (1.00)	76.1%	28	4.23 (.97)	5 (2.00)	75%	MET

Table 26: Round 2, Topic 2

TOPIC 2: DETAILS OF THE CARE PROVIDED BY THE YOUNG PERSON **How important is it to ask the young person...**		**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria Met** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
1	...about the type of things they do to help in their caring role?	94	3.99 (.96)	4 (2.00)	72.4%	67	4.28 (.79)	4 (1.00)	85%	27	3.23 (.97)	3 (1.00)	40%	QUERY
2	...if they are providing emotional support, e.g. keeping company or comforting?	94	4.10 (.91)	4 (1.75)	74.5%	67	4.21 (.79)	4 (1.00)	79.1%	27	3.82 (**1.13**)	4 (2.00)	62.9%	MET
3	...if they are helping with personal care, e.g. washing, dressing?	94	4.11 (.94)	4 (1.00)	75.5%	67	4.40 (.70)	5 (1.00)	91%	27	3.36 (**1.10**)	3 (1.00)	37%	QUERY
4	...if they are helping with practical household tasks, e.g. cleaning, laundry?	93	3.76 (.96)	4 (2.00)	59.1%	66	3.93 (.87)	4 (2.00)	68.2%	27	3.32 (**1.04**)	3 (1.00)	37%	QUERY
5	...if they are providing physical support, e.g. lifting, moving?	94	4.20 (.86)	4 (2.00)	74.5%	67	4.38 (.74)	5 (1.00)	86.5%	27	3.73 (.98)	3 (2.00)	44%	QUERY
6	...if they are giving medication to the person they care for, or checking it has been taken?	94	4.49 (.81)	5 (1.00)	88.3%	67	4.69 (.63)	5 (1.00)	95.5%	27	3.95 (.99)	4 (2.00)	70.3%	MET
7	...if they are attending appointments with the person they care for?	94	3.96 (**1.02**)	4 (2.00)	69.2%	67	4.14 (.85)	4 (2.00)	76.1%	27	3.5 (**1.30**)	4 (2.25)	51.8%	QUERY
8	...if they are looking after siblings?	93	4.00 (.93)	4 (2.00)	67.8%	66	4.15 (.81)	4 (1.00)	77.3%	27	3.60 (**1.10**)	3 (2.00)	44.4%	QUERY
9	...if they are undertaking tasks they don't want to do?	94	4.30 (1.00)	5 (1.00)	79.8%	67	4.60 (.70)	5 (1.00)	89.5%	27	3.50 (**1.22**)	4 (1.25)	55.5%	QUERY

Table 26: Round 2, Topic 3

TOPIC 3: THE YOUNG CARERS OWN HEALTH AND WELLBEING **How important is it to ask the young person...**		**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
1	...if they need support with their physical health?	93	4.14 (.87)	4 (2.00)	74.2%	67	4.36 (.79)	5 (1.00)	89.5%	26	3.54 (.80)	3 (1.00)	34.6%	QUERY
2	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?	93	4.54 (.78)	5 (1.00)	90.3%	67	4.74 (.55)	5 (0)	98.5%	26	4.00 (**1.02**)	4 (2.00)	69.2%	MET
3	...if they have a friend or family member they can speak to or contact for help or support?	93	4.30 (.88)	5 (1.00)	79.6%	67	4.46 (.75)	5 (1.00)	88.1%	26	3.68 (**1.04**)	4 (2.00)	57.7%	QUERY
4	...if they spend time with their friends?	93	4.28 (.86)	4 (1.00)	81.7%	67	4.45 (.70)	5 (1.00)	88%	26	3.68 (**1.04**)	4 (1.25)	65.4%	MET
5	...if they spend time with their family members?	92	3.94 (.89)	4 (2.00)	66.5%	66	4.10 (.76)	5 (1.00)	77.2%	26	3.50 (**1.06**)	3 (2.00)	38.5%	QUERY
6	...if they want a break or time away from their caring role?	92	4.06 (**1.02**)	5 (1.00)	82.6%	66	4.40 (.75)	5 (1.00)	86.4%	26	4.04 (**1.04**)	4 (2.00)	73.1%	MET
7	...if they attend/receive support from a young carers' service?	93	4.06 (**1.02**)	4 (2.00)	69.9%	67	4.22 (.96)	5 (1.00)	79.1%	26	3.64 (**1.10**)	4 (2.00)	46.2%	QUERY
8	...if they need help accessing a group, or any other clubs in their schools or local community?	92	3.96 (**1.01**)	4 (2.00)	69.6%	67	4.24 (.76)	4 (1.00)	80.6%	25	3.27 (**1.24**)	3 (2.00)	40%	QUERY

Table 26: Round 2, Topic 4

TOPIC 4: THE YOUNG CARERS IDENTITY AND SELF ESTEEM **How important is it to ask the young person...**		**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
1	...whether they see themselves as a young carer?	90	3.41 (1.00)	3 (1.00)	37.8%	64	3.5 (**1.01**)	3 (1.00)	42.2%	26	3.18 (.96)	3 (1.25)	26.9%	REMOVE
2	...if they feel recognised and supported by others for their caring role?	90	3.79 (.94)	4 (1.75)	62.2%	64	4.00 (.75)	4 (2.00)	71.9%	26	3.23 (**1.15**)	3 (2.00)	38.4%	QUERY
3	...if they feel bullied or stigmatised by others for their caring role?	90	4.36 (.85)	5 (1.00)	86.7%	64	4.41 (.73)	5 (1.00)	87.6%	26	4.23 (**1.11**)	5 (1.00)	84.6%	MET
4	...if they want or need support speaking to people about their caring role?	90	4.28 (.86)	4 (1.00)	82.3%	64	4.43 (.70)	5 (1.00)	89.1%	26	3.86 (**1.08**)	4 (2.00)	65.4%	MET
5	...if they have someone who can speak on their behalf, if necessary?	89	4.09 (.83)	4 (2.00)	73%	64	4.24 (.73)	4 (1.00)	84.4%	25	3.68 (.95)	3 (2.00)	44%	QUERY

Table 26: Round 2, Topic 5

	TOPIC 5: EDUCATION AND FUTURE PLANS **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**60% Criteria Met (Total % who rated it 4 or 5)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**60% Criteria Met (Profs % who rated it 4 or 5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**60% Criteria Met (Young Carers % who rated it 4 or 5)**	**Criteria** (If met for keeping note MET, if not note REMOVE, if disagreed note QUERY)
1	...if there is a named staff member at their school/college for young carers?	90	3.85 (.96)	4 (2.00)	60%	64	4.02 (.80)	4 (2.00)	71.9%	26	3.41 (**1.18**)	3 (2.00)	30.8%	QUERY
2	...if they want or need help to make staff at school/college aware of their caring role?	90	4.13 (.80)	4 (1.00)	77.7%	64	4.28 (.67)	4 (1.00)	86%	26	3.73 (.98)	4 (1.25)	57.7%	QUERY
3	...if there are specific needs they have in school/college, e.g. extra time for homework?	90	4.05 (.87)	4 (1.00)	80%	64	4.19 (.80)	4 (1.00)	84.4%	26	3.68 (.95)	4 (1.00)	69.2%	MET
4	...if there is anything that could help reduce stress/anxiety at or about school/college?	90	4.43 (.74)	5 (1.00)	94.4%	64	4.53 (.60)	5 (1.00)	98.4%	26	4.14 (.99)	4 (1.00)	84.7%	MET
5	...if they need additional advice/support about future education or career options?	90	4.06 (.93)	4 (1.00)	77.8%	64	4.14 (.80)	4 (1.00)	81.3%	26	3.86 (**1.21**)	4 (2.00)	69.3%	MET
6	...if they intend to continue in their caring role after leaving school/college?	89	3.87 (.91)	4 (2.00)	67.4%	64	3.98 (.85)	4 (2.00)	75%	25	3.60 (**1.01**)	4 (1.25)	48%	QUERY

Appendix 13: R3 Responses to Topics 1-5 (Full Table) Round Three

Participants from both cohorts rated the 23 items that did not reach consensus in Round 2 on a 5 point Likert scale, with (1) being *'not at all important'*, (3) being '*important'* and (5) being '*extremely important'*. The table below presents the sample, mean and standard deviation, median and interquartile range (IQR), and consensus level for each item. SDS>1 are in bold to highlight items with more spread in their ratings.

Criterion for accepting an item: at least 60% of the young carers and professional cohorts rated an item as (4) *'very important'* or (5) *'extremely important' (noted as MET).*

Criterion for rejecting an item: any items that did not meet the 60% criteria by either or both cohorts (noted as REMOVE).

Table 34: Round 3 Full Table Topic 1

	TOPIC 1: UNDERSTANDING THE CARING SITUATION **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**Total Sample who rated it 4 or 5 (%)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**Total Profs who rated it 4 or 5 (%)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**Total Young Carers who rated it 4 or 5 (%)**	**Criteria (If 60% met note MET, if disagreed note QUERY, if 60% not met note REMOVE)**
1	...how long they have been caring for someone in their family?	110	3.49 **(1.01)**	3 (1.00)	56 (50.9%)	74	3.67 (0.95)	4 (1.00)	43 (58.1%)	36	3.13 **(1.05)**	3 (2.00)	13 (36.1%)	**REMOVE**
2	...how much time they spend on average caring each day/week?	109	3.83 **(1.08)**	4 (2.00)	71 **(65.2%)**	73	3.94 (0.96)	4 (2.00)	49 **(67.1%)**	36	3.61 **(1.28)**	4 (3.00)	22 **(61.1%)**	**MET**
3	...if they need support to continue their caring role?	109	4.51 (0.75)	5 (1.00)	97 **(89%)**	74	4.68 (0.59)	5 (1.00)	70 **(94.6%)**	36	4.16 (0.93)	4 (1.00)	27 **(77.2%)**	**MET**
4	...if they need practical support or training to help them provide care?	109	3.73 **(1.13**)	4 (2.00)	72 (66.1%)	73	3.89 **(1.10)**	4 (2.00)	51 (69.9%)	36	3.42 **(1.11)**	4 (1.00)	21 (58.4%)	**REMOVE**

	TOPIC 1: UNDERSTANDING THE CARING SITUATION **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**Total Sample who rated it 4 or 5 (%)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**Total Profs who rated it 4 or 5 (%)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**Total Young Carers who rated it 4 or 5 (%)**	**Criteria (If 60% met note MET, if disagreed note QUERY, if 60% not met note REMOVE)**
5	...if they want or need information about their family member's condition/disability?	110	3.89 (0.91)	4 (2.00)	76 (69.1%)	74	3.74 (0.96)	4 (2.00)	63 (75.6%)	36	3.74 (0.96)	4 (2.00)	20 (55.5%)	**REMOVE**
6	...if they feel included in support decisions about their family member?	110	4.1 (0.89)	4 (1.25)	85 **(77.3%)**	74	4.32 (0.84)	5 (1.00)	63 **(85.1%)**	36	3.64 (0.84)	4 (1.00)	22 **(61.1%)**	**MET**

Table 34: Round 3, Topic 2

	TOPIC 2: DETAILS OF THE CARE PROVIDED BY THE YOUNG PERSON **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**Total Sample who rated it 4 or 5 (%)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**Total Profs who rated it 4 or 5 (%)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**Total Young Carers who rated it 4 or 5 (%)**	**Criteria (If 60% met note MET, if disagreed note QUERY, if 60% not met note REMOVE)**
1	...about the type of things they do to help in their caring role?	108	4.21 (0.87)	4 (1.00)	87 **(80.6%)**	73	4.38 (0.77)	5 (1.00)	66 **(90.4%)**	36	3.87 (0.96)	4 (2.00)	21 **(60%)**	**MET**
2	...if they are helping with personal care, e.g. washing, dressing?	108	3.96 **(1.18)**	4 (2.00)	78 (72.2%)	73	4.41 (0.85)	5 (1.00)	64 (87.7%)	36	3.03 **(1.25)**	3 (2.00)	14 (40%)	**REMOVE**
3	...if they are helping with practical household tasks, e.g. cleaning, laundry?	108	3.66 **(1.03)**	4 (1.00)	67 (62.1%)	73	3.86 (0.91)	4 (2.00)	49 (67.1%)	35	3.26 **(1.15)**	3 (2.00)	18 (51.4%)	**REMOVE**

	TOPIC 2: DETAILS OF THE CARE PROVIDED BY THE YOUNG PERSON **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**Total Sample who rated it 4 or 5 (%)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**Total Profs who rated it 4 or 5 (%)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**Total Young Carers who rated it 4 or 5 (%)**	**Criteria (If 60% met note MET, if disagreed note QUERY, if 60% not met note REMOVE)**
4	...if they are providing physical support, e.g. lifting, moving?	105	4.1 (1.05)	4 (1.25)	79 (75.3%)	70	4.44 (0.84)	5 (1.00)	61 (87.2%)	35	3.39 (1.08)	4 (1.00)	18 (51.4%)	**REMOVE**
5	...if they are attending appointments with the person they care for?	108	3.88 **(1.00)**	4 (2.00)	74 (68.5%)	73	4.08 (0.92)	4 (2.00)	54 (74%)	35	3.48 **(1.06)**	4 (1.00)	20 (57.2%)	**REMOVE**
6	...if they are looking after siblings due to a parent's poor health?	106	4.18 (0.94)	4 (1.00)	89 **(84%)**	73	4.36 (0.79)	5 (1.00)	64 **(87.7%)**	35	3.81 **(1.11)**	4 (2.00	25 **(75.7%)**	**MET**
7	...if they are undertaking tasks they don't want to do?	108	4.51 (0.77)	5 (1.00)	91 **(84.3%)**	73	4.68 (0.67)	5 (0)	66 **(90.4%)**	35	4.6 (0.90)	4 (2.00)	25 **(71.5%)**	**MET**

Table 34: Round 3, Topic 3

	TOPIC 3: THE YOUNG CARERS OWN HEALTH AND WELLBEING **How important is it to ask the young person...**	**Total Sample (N)**	**Total Sample Mean (SD)**	**Total Sample Median (IQR)**	**Total Sample who rated it 4 or 5 (%)**	**Profs (N)**	**Profs Mean (SD)**	**Profs Median (IQR)**	**Profs who rated it 4 or 5 (5)**	**Young Carers (N)**	**Young Carers Mean (SD)**	**Young Carers Median (IQR)**	**Young Carers who rated it 4 or 5 (%)**	**Criteria** (If 60% met by both cohorts note MET, if 60% not met note REMOVE)
1	...if they need support with their physical health?	108	4.20 (0.81)	4 (1.00)	89 (82.4%)	73	4.25 (0.78)	4 (1.00)	58 (82.1%)	35	4.10 (0.87)	4 (1.00)	29 (82.9%)	MET
3	...if they have a friend or family member they can speak to or contact for help or support?	108	4.36 (0.85)	5 (1.00)	93 (86.1%)	73	4.50 (0.78)	5 (1.00)	66 (90.5%)	35	4.06 (0.93)	4 (2.00)	27 (77.1%)	MET
5	...if they spend time with their family members?	106	3.91 (0.91)	4 (2.00)	73 68.8%	71	4.08 (0.87)	4 (1.00)	57 (80.3%)	35	3.58 (0.92)	3 (1.00)	16 (45.7%)	REMOVE
7	...if they attend/receive support from a young carers' service?	108	3.90 (1.01)	4 (2.00)	75 (69.5%)	73	4.09 (0.91)	4 (2.00)	53 (72.6%)	35	3.77 (1.17)	4 (2.00)	22 (62.9%)	MET
8	...if they need help accessing a group, or any other clubs in their schools or local community?	107	4.02 (1.01)	4 (1.00)	82 (76.6%)	73	4.22 (0.87)	4 (1.00)	58 (82.1%)	34	3.61 (1.17)	4 (1.00)	22 (64.7%)	MET

Table 34: Round 3, Topic 4

	TOPIC 4: THE YOUNG CARERS IDENTITY AND SELF ESTEEM How important is it to ask the young person...	Total Sample (N)	Total Sample Mean (SD)	Total Sample Median (IQR)	Total Sample who rated it 4 or 5 (%)	Profs (N)	Profs Mean (SD)	Profs Median (IQR)	Total Profs who rated it 4 or 5 (%)	Young Carers (N)	Young Carers Mean (SD)	Young Carers Median (IQR)	Total Young Carers who rated it 4 or 5 (%)	Criteria (If 60% met by both note MET, if 60% not met by both, note REMOVE
1	...if they feel recognised and supported by others for their caring role?	108	3.79 **(1.00)**	4 (2.00)	71 (65.7%)	73	3.90 (0.87)	4 (2.00)	51 (69.5%)	35	3.55 **(1.21)**	4 (2.00)	20 (57.2%)	**REMOVE**
2	...if they have someone who can speak on their behalf, if necessary?	107	4.10 (0.97)	4 (2.00)	79 **(73.9%)**	73	4.22 (0.88)	4 (1.00)	55 **(76.4%)**	35	3.87 **(1.12)**	4 (2.00)	24 **(68.6%)**	**MET**

Table 34: Round 3, Topic 5

	TOPIC 5: EDUCATION AND FUTURE PLANS How important is it to ask the young person...	Total Sample (N)	Total Sample Mean (SD)	Total Sample Median (IQR)	Total Sample who rated it 4 or 5 (%)	Profs (N)	Profs Mean (SD)	Profs Median (IQR)	Total Profs who rated it 4 or 5 (%)	Young Carers (N)	Young Carers Mean (SD)	Young Carers Median (IQR)	Total Young Carers who rated it 4 or 5 (%)	Criteria (If 60% met by both note MET, if 60% not met by both, note REMOVE)
1	...if there is a named staff member at their school/college for young carers?	107	3.89 **(1.08)**	4 (2.00)	72 **(67.2%)**	72	4.02 **(1.04)**	4 (2.00)	51 **(70.9%)**	35	3.64 **(1.14)**	4 (2.00)	21 **(60%)**	**MET**
2	...if they want or need help to make staff at school/college aware of their caring role?	107	4.19 (0.98)	4 (1.00)	88 **(82.2%)**	72	4.27 (0.88)	4 (1.00)	61 **(84.7%)**	35	4.03 **(1.17)**	4 (2.00)	27 **(77.1%)**	**MET**
3	...if they intend to continue in their caring role after leaving school/college?	106	3.83 **(1.21)**	4 (2.00)	70 (66%)	71	3.98 **(1.10)**	4 (2.00)	50 (70.5%)	35	3.52 **(1.39)**	4 (3.00)	20 (57.1%)	**REMOVE**

Appendix 14: Items reaching 60% consensus by both cohorts for consideration to send to the Expert Panel

The table below presents all 26 items within their topics that reached 60% or more consensus by each cohort rating an item as (4) '*very important*' or (5) *'extremely important'* after both rounds.

Additionally, the total sample, Delphi round, Mean and standard deviation (SD) for the items reaching consensus are included in the table. The items within each topic are numbered to reflect their original position in the first survey (R2) of 37 items.

Rounds 2 & 3, 60% and Higher Consensus Table

TOPIC 1: UNDERSTANDING THE CARING SITUATION How important is it to ask the young person...		Total sample = N & (round)	% Total sample who rated it 4 or 5	Profs Mean (SD)	Young Carers Mean (SD)	Total Sample Mean (SD)
2	...how much time they spend on average caring each day/week?	109 (R3)	65%	3.94 (0.96)	3.61 (1.28)	3.83 (1.08)
3	...if they have support from another adult in the home?	96 (R2)	84%	4.52 (0.63)	3.86 (1.03)	4.34 (0.75)
4	...if they need support to continue their caring role?	109 (R3)	89%	4.68 (0.59)	4.16 (0.93)	4.51 (0.75)
6	...if they need support with financial matters, e.g. benefits, housing?	94 (R2)	72%	4.19 (0.83)	3.91 (1.38)	4.11 (1.01)
8	...if they feel included in support decisions about their family member?	110 (R3)	77%	4.32 (0.84)	3.64 (0.84)	4.10 (0.89)
9	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	95 (R2)	91%	4.69 (0.50)	4.23 (0.97)	4.56 (0.69)

	TOPIC 2: DETAILS OF THE CARE PROVIDED BY THE YOUNG PERSON How important is it to ask the young person...	Total sample = N & (round)	% of total sample who rated it 4 or 5	Profs Mean (SD)	Young Carers Mean (SD)	Total sample Mean (SD)
1	...about the type of things they do to help in their caring role?	108 (R3)	81%	4.38 (0.77)	3.87 (0.96)	4.21 (0.87)
2	...if they are providing emotional support, e.g. keeping company or comforting?	94 (R2)	75%	4.74 (0.55)	3.82 (1.13)	4.10 (0.91)
6	...if they are giving medication to the person they care for, or checking it has been taken?	94 (R2)	88%	4.69 (0.63)	3.95 (0.99)	4.49 (0.81)
8	...if they are looking after siblings (due to a parent's poor health*)? (* extra words added between rounds, following feedback)	106 (R3)	84%	4.36 (0.79)	3.81 (1.11)	4.18 (0.94)
9	...if they are undertaking tasks they don't want to do?	108 (R3)	84%	4.68 (0.67)	4.16 (0.9)	4.51 (0.77)

	TOPIC 3: THE YOUNG CARERS OWN HEALTH AND SOCIAL WELLBEING How important is it to ask the young person...	Total sample = N & (round)	% of total sample who rated it 4 or 5	Profs Mean (SD)	Young Carers Mean (SD)	Total sample Mean (SD)
1	...if they need support with their physical health?	108 (R3)	82%	4.25 (0.78)	4.10 (0.87)	4.20 (0.81)
2	...if they need support with their emotional wellbeing, e.g. counselling, advice on coping strategies?	93 (R2)	90%	4.74 (0.55)	4.00 (1.02)	4.54 (0.78)
3	...if they have a friend or family member they can speak to or contact for help or support?	108 (R3)	86%	4.50 (0.78)	4.06 (0.93)	4.36 (0.85)
4	...if they spend time with their friends?	90 (R2)	82%	4.45 (0.70)	3.68 (1.04)	4.24 (0.86)
6	...if they want a break or time away from their caring role?	92 (R2)	83%	4.40 (0.75)	4.04 (1.04)	4.30 (0.85)
7	...if they attend/receive support from a young carers' service?	108 (R3)	70%	4.09 (0.91)	3.77 (1.17)	3.90 (1.01)
8	...if they need help accessing a group, or any other clubs in their schools or local community?	107 (R3)	77%	4.22 (0.87)	3.61 (1.17)	4.02 (1.01)

TOPIC 4: THE YOUNG CARERS IDENTITY AND SELF-ESTEEM How important is it to ask the young person...		Total sample = N & (round)	% of total sample who rated it 4 or 5	Profs Mean (SD)	Young Carers Mean (SD)	Total sample Mean (SD)
3	...if they feel bullied or stigmatised by others for their caring role?	90 (R2)	87%	4.41 (0.70)	4.23 (1.11)	4.36 (0.85)
4	...if they want or need support speaking to people about their caring role?	90 (R2)	82%	4.43 (0.70)	3.86 (1.08)	4.28 (0.86)
5	...if they have someone who can speak on their behalf, if necessary?	107 (R3)	74%	4.22 (0.88)	3.87 (1.12)	4.10 (0.97)

TOPIC 5: EDUCATION AND FUTURE PLANS How important is it to ask the young person...		Total sample = N & (round)	% of total sample who rated it 4 or 5	Profs Mean (SD)	Young Carers Mean (SD)	Total sample Mean (SD)
1	...if there is a named staff member at their school/college for young carers?	107 (R3)	67%	4.02 (1.04)	3.64 (1.14)	3.89 (1.08)
2	...if they want or need help to make staff at school/college aware of their caring role?	107 (R3)	82%	4.27 (0.88)	4.03 (1.17)	4.19 (0.98)
3	...if there are specific needs they have in school/college, e.g. extra time for homework?	90 (R2)	80%	4.19 (0.80)	3.68 (0.95)	4.05 (0.87)
4	...if there is anything that could help reduce stress/anxiety at or about school/college?	90 (R2)	94%	4.53 (0.60)	4.14 (0.99)	4.43 (0.74)
5	...if they need additional advice/support about future education or career options?	90 (R2)	78%	4.14 (0.80)	3.86 (1.21)	4.06 (0.93)

Appendix 15: Top 10 ranked items by the professionals in the expert panel (n=8) for inclusion in the CAT-YC

Table 42: Top 10 ranked items by the professionals

Topic (& original Item No. within topic)	Top Items ranked by overall Mean: How important is it to ask the young person...	Ranking Position	Mean Ranking* (SD)
2 (9)	...if they are undertaking tasks they don't want to do	1	**2.50** (1.60)
3 (3)	...if they have a friend or family member they can speak to or contact for help or support?	2	**4.14** (2.91)
3 (2)	...if they need support with their own health or emotional wellbeing, e.g. counselling, advice on coping strategies?	3	**4.75** (3.69)
5 (4)	...if there is anything that could help reduce stress/anxiety at or about school/college?	4	**5.80** (1.64)
1 (9)	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	=5	**6.00** (4.16)
3 (1)	...if they need support with their physical health	=5	**6.00** (4.06)
4 (3)	...if they feel bullied or stigmatised by others for their caring role?	7	**6.25** (2.87)
1 (3)	...if they have support from another adult in the home?	8	**6.50** (2.88)
2 (1)	...about the type of things they do to help in their caring role?	9	**6.83** (5.60)
1 (4)	...if they need support to continue their caring role?	10	**7.17** (4.87)

*Items were ranked from (1) as the highest ranked item, so the items ranked highest have the lowest mean.

Appendix 16: Top 10 ranked items by the young carers in the expert panel (n=11) for inclusion in the CAT-YC

Table 43: Top 10 ranked items by the young carers

Topic (& original Item No. within topic)	Top Items ranked by overall Mean: How important is it to ask the young person...	Ranking Position	Mean Ranking* (SD)
3 (2)	...if they need support with their own health or emotional wellbeing, e.g. counselling, advice on coping strategies?	1	**3.45** (1.97)
2 (9)	...if they are undertaking tasks they don't want to do	2	**3.75** (3.73)
1 (9)	...if they have a plan of who to contact in case of an emergency, or during out of hours care, e.g. when GP is closed?	3	**4.17** (2.86)
1 (3)	...if they have support from another adult in the home?	4	**4.57** (4.61)
5 (4)	...if there is anything that could help reduce stress/anxiety at or about school/college?	5	**5.22** (1.86)
2 (6)	...if they are giving medication to the person they care for, or checking it has been taken?	6	**5.38** (3.58)
1 (4)	...if they need support to continue their caring role?	7	**5.56** (4.61)
2 (1)	...about the type of things they do to help in their caring role?	8	**5.83** (2.86)
3 (3)	...if they have a friend or family member they can speak to or contact for help or support?	9	**7.00** (2.83)
3 (6)	...if they want a break or time away from their caring role?	10	**7.44** (3.57

*Items were ranked from (1) as the highest ranked item, so the items ranked highest have the lowest mean.

Appendix 17: **Phase 3 Interview Schedule for Young Carers**

Edge Hill University

Semi-Structured Interview Schedule for Young Carers (Evaluation Phase 3)

Introductions and Explanations:

- Remind young person who I am and what the study is about
- Thank the young person for taking part
- Revisit information and check assent/consent sheets have been signed by themselves and a parent/guardian (if 11-15) or if it is a telephone interview with a young person aged 16-18, confirm verbal consent to proceed
- Explain that it is okay to pause or stop the interview, take a break, move on to another question, rearrange for another day or time, or end the interview
- Show them the audio-recorder (if a face to face interview) and confirm their understanding of why I will be recording the interview

(Spend a few minutes talking about general things to help them settle and feel more at ease)

Gather some demographic information:

- Age
- Family composition – who they live with; if they have brothers and/or sisters, are they older/younger?
- Who they help care for
- How long they have been helping care for their family member (*use name, or mum/dad/brother/nan, as appropriate*)
- Do they know why their family member (*name –X - as above*) needs care?

Interview Questions:

1. **I'd like to ask you about your experience of completing the CAT-YC with** (*name of staff member*)

2. **Did you feel that the CAT-YC form took the right amount of time to complete?**
   (*Prompts: too long/too short? Can you remember how long it took?*)

3. **How did you find the questions on the CAT-YC?**
   (*Prompts: were they what you expected?)*

4. **In what ways did the questions help you to talk about any worries you have?**
   (Prompt: can you remember what these were?)

5. **Did the questions lead to you getting any information you didn't have, or being referred for further support?**
   (Prompts: what type of information/support? Where from?)

6. **What questions do you think might have been missing from the CAT-YC?**
   (*Prompts: is there anything important we may have forgotten?)*

7. **Have you had a young carers' assessment?**
   (Prompts: someone asking you about your needs as a young carer?)

   a) *(If yes)* **When did you have this?**
      (Prompts: who did it? How long did you wait? Did anything change?)

8. **How often do you think the CAT-YC should be used?**
   (*Prompt: Just once, every 3 months? 6 months? Yearly?)*

9. **If someone were to ask you about your needs or worries as a young carer regularly, who would you rather it be?**
   (*Prompts: staff at the centre/teacher/school nurse/GP...someone else?)*

10. **Is there anything else you want to say about being a young carer or using the CAT-YC?**
    (Prompts: anything important I might have missed? Anything you weren't sure of? Any last words before we finish?)

Endings:

- Check the young person is okay (*provide support organisation details as required)*
- Thank them for taking part
- Spend a few minutes bringing the conversation back to general things – (e.g. what are your plans for the rest of the day?)
- If the interview is at a young carers' centre, ensure they are delivered back to a staff member. If the interview is at home, thank their parent/legal guardian before leaving.

Appendix 18: **Phase 3 Interview Schedule for Professionals**

Edge Hill University

Semi-Structured Interview Schedule for Staff (Evaluation Phase 3)

Introductions and Explanations:

- Introduce myself (or greet them, if previously met) and remind them of the purpose of the interview
- Thank them for taking part
- Ask them to sign consent form if in person, or confirm verbal consent before proceeding

Gather some demographic information:

- What is their role at the young carers centre?
- How long have they worked there?

Interview Questions:

I'd like to ask you about your experience of completing the CAT-YC with young carers.

11. **Please tell me about your experience of introducing the CAT-YC with young carers?**
    (*Prompts: Did anyone not want to do it? If yes – did they give a reason?)*

12. **How did you find using the CAT-YC with young carers?**
    (*Prompts: Clarity of instructions?*
    Readability and appropriateness of questions?
    Alert scoring?
    Time it took to complete?
    Prioritising any alerts/next steps?

13. **Did the questions lead to further discussion about any needs or concerns that were not included in the CAT-YC??**
    (If yes – can you remember what these were?

14. **Typically, what type of actions/next steps did you take in response to any priorities alerts?**
    (Prompts: Referrals/Information/Services/Support?)

15. **Was there anything you felt was missing from the CAT-YC?**

(*Prompts: is there anything important we may have forgotten?)*

16. **Do you think the CAT-YC can identify areas of need that could pose a risk for the carer's own well-being?**

17. **Do you think screening young carers with the CAT-YC would be helpful?**
    (*Prompts: For the young carer? For the organisation using it?)*

18. **Do you think using the CAT-YC regularly would be helpful?**
    (*If yes – how often do you think? 3 months? 6 months? Yearly? Considering confidentiality -where should it be stored?)*

19. **Who do you think is best placed to complete the CAT-YC?**
    (*Prompts: Staff at the centre/teacher/school nurse/GP...someone else?)*

20. **Is there anything else you want to say about using the CAT-YC before we finish?**
    (Prompts: anything important I might have missed? Anything you weren't sure of?)

Endings:

- Thank them for taking part
- Ask them to remind young carers who have expressed an interest in participating to bring back consent forms and/or ask their parent/legal guardian to contact me or a staff member at the centre (if under 16) to arrange an interview date and time

Appendix 19: Email from Barnardo's

From: Bridgit Carey <bridgit.carey@barnardos.org.uk>
Date: Friday, 31 May 2019 at 15:27
To: Lynn Kettell <Kettelll@edgehill.ac.uk>, Angela Howard <angela.howard@barnardos.org.uk>
Subject: Re: CAT-YC Tool - next steps!

Hello Lynn

I hope that all is well with you.

I am copying Angela Howard into this e-mail; Angela is our Development Worker, relatively new in post, but already working on an initiative with schools on the back of the Section 175 safeguarding audit. For information I have attached a 2016 document which I found online for Liverpool, but it's likely that there is a more up to date version… the reference to young carers is on page 19.

Angela and schools have identified the need for a tool which education professionals can use to assist in the identification and immediate support of young carers and that tool seems to be the CAT-YC.

It is possible that this is where your research began some years ago, so my apologies if it is.

Anyway… we are wondering how close you are to completing the evaluation of your pilot, and making the tool available for use.

Angela has a meeting with senior leads next week (beginning 3rd June) and will introduce your tool as the document that schools might use going forward, if you think that it will be ready to run from September 2019.

I appreciate that there may be copyright issues etc. which will need addressing but in principle, does this sound like something we can do?

Please liaise with Ange on this… I'm really just putting you in contact with each other, but I do hope that all goes well.

Kind regards

Bridgit

Appendix 20: Recommendations for the Conducting and REporting of DElphi Studies (CREDES)

(Jünger et al. 2017: 701-702)

Rationale for the choice of the Delphi technique

1. *Justification*. The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature

Planning and design

2. *Planning and process*. The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously
3. *Definition of consensus*. Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations
4. *Study conduct*. Informational input. All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias
5. *Prevention of bias*. Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable
6. *Interpretation and processing of results.* Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question
7. *External validation*. It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before publication and dissemination

Reporting

8. *Purpose and rationale*. The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided
9. *Expert panel*. Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported
10. *Description of the methods.* The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process
11. *Procedure.* Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps
12. *Definition and attainment of consensus*. It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus
13. *Results.* Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds
14. *Discussion of limitations.* Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance
15. *Adequacy of conclusions*. The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance
16. *Publication and dissemination*. The resulting guidance on good practice in palliative care should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process (e.g. persistent disagreement and controversy on certain issues)). A dissemination plan should include endorsement of the guidance by professional associations and health care authorities to facilitate implementation

Appendix 21: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

(Tong et al. 2007:352)

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal characteristics		
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3	Occupation	What was their occupation at the time of the study?
4	Gender	Was the researcher male or female?
5	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6	Relationship established	Was a relationship established prior to study commencement?
7	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *e.g. Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*
12	Sample size	How many participants were in the study?
13	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14	Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*
15	Presence of non-participants	Was anyone else present besides the participants and researchers?
16	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20	Field notes	Were field notes made during and/or after the interview or focus group?
21	Duration	What was the duration of the interviews or focus group?
22	Data saturation	Was data saturation discussed?
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24	Number of data coders	How many data coders coded the data?
25	Description of the coding tree	Did authors provide a description of the coding tree?
26	Derivation of themes	Were themes identified in advance or derived from the data?
27	Software	What software, if applicable, was used to manage the data?
28	Participant checking	Did participants provide feedback on the findings?
Reporting		
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g. participant number*
30	Data and findings consistent	Was there consistency between the data presented and the findings?
31	Clarity of major themes	Were major themes clearly presented in the findings?
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Appendix 22: Post-Script and Study Reflections

It is not usual practice to provide personal reflections in a mixed-method study; however, it feels incomplete not to finish my thesis by reflecting on the study process. The preface to the thesis set out my reasons for wanting to develop the CAT-YC; although I have addressed how the study was conducted, I would like to say more about how I found the process, now that it has ended.

There were a number of moments that were challenging. The first came during phase one when one of the three young carer groups I had built a relationship with lost their contract and had to withdraw from the study. In the same week, another of the groups withdrew support due to staff resource issues, and the third group also had a change of staff that delayed recruitment plans by six weeks. I found myself wondering if the study would ever get off the ground, but decided to waste no time worrying and instead set about forging links with other groups.

Another disappointing time was during preliminary analysis of survey data in phase two. The consensus level for the Delphi had been pre-set to 70% of participants in both the young carer and professional cohorts rating an item as equal to or greater than a median level of (4) *'very important'* on a five-point Likert scale. However, due to the diffuse levels of consensus amongst the young carer cohort, this level had to be lowered to 60% in order to achieve its aim. Although there is no clearly defined acceptable level for consensus (Keeney, Hasson and McKenna, 2011), this had nevertheless not been anticipated beforehand and was therefore initially disappointing. On reflection the disparity was understandable, as many of the young carers in the small consensus group meetings appeared to relate the survey items to their own individual circumstances, rather than generically as the professionals had done. This led to making minor changes in how data were collected in round three of the Delphi survey, which ultimately gave me a greater depth of understanding about the participants' responses. However, I feel it is important for my integrity as a researcher to acknowledge my initial disappointment of the findings in this phase.

There were also many high points throughout the study process. Interviewing young carers in the first phase was particularly rewarding and one comment that was made by one of the first participants I interviewed, stayed with me throughout the study:

> *'On bad days it really does affect how I feel, because – it's really cringy, actually thinking about it - I care about my mum a lot. I'm seeing her, when she is on a bad day...it absolutely breaks my heart'* (Joe, 16)

This reminded me that developing the CAT-YC was not just about the practical ways that unmet needs could be identified, triaged and supported, but also about providing the opportunity for young carers to talk to somebody about their situation and be listened to, even if they had no immediate needs. This was really important to me, as I feel that young people are often not given enough space to talk about their feelings. Using the CAT-YC will hopefully help to give them that voice.

Another high point came following the evaluation of the pilot study, when I was contacted by Barnardo's and asked to attend a meeting to discuss when they could officially start using the CAT-YC, as they thought it would be a really useful tool for them as an organisation. There will, of course, need to be further piloting on a larger scale to establish validity first, however, it was both encouraging and validating to hear their enthusiasm about it in the subsequent meeting. Similarly, I have received enquiries from a number of young carer groups and schools nationally about wanting to use the CAT-YC. A final high point during the study period came when a paper I had written about young adult carers (Kettell, 2018), was cited by the widely acknowledged world leading experts on young carers, Professors Saul Becker and Stephen Joseph, in a narrative review they had co-authored (Joseph et al. 2019). This has given me the motivation and confidence to write more papers, that are based on this study's findings.

Overall, the learning and work I have undertaken over the past three years has been incredibly rewarding. I hope the resultant CAT-YC may help in instigating a difference to some young people's lives in the future.